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Mitchell, Helen Louise

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**THE NATURE AND ROLE OF PATIENT EXPECTATIONS IN
EXERCISE BEHAVIOUR IN OSTEOARTHRITIS**

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This thesis is submitted to King's College London for the degree of
Doctor of Philosophy



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ABSTRACT

The purpose of this thesis was to explore the area of expectations and examine their role in exercise behaviour in individuals with knee osteoarthritis (OA).

In a systematic review on the role of expectations in interventions for chronic musculoskeletal joint pain, positive expectations were consistently related to positive outcomes. However, only three studies were suitable and a number of methodological problems with measuring expectations were identified.

A cross-sectional qualitative study explored outcome and treatment expectations and findings were used to develop a questionnaire to measure OA-related beliefs. In a second qualitative study a small number of participants were re-interviewed a year later to examine how the condition and perceptions of the condition had changed. Findings suggest expectations are malleable and respond to new information.

The Knee Pain Beliefs Questionnaire (KPBQ) was developed from the qualitative data and consisted of four factors, including two on expectations (future state/illness expectations and defensive optimism). The measure showed satisfactory internal reliability, test-retest reliability and discriminant validity.

The KPBQ was used to measure expectations in a sample of primary care OA patients. Questionnaires were completed at baseline (time 1), time 2 (approximately 8 weeks after baseline) and time 3 (approximately 8 months after baseline).

In the cross-sectional analyses of these data ($N=80$), illness expectations and defensive optimism were more strongly related to activity levels than outcome or self-efficacy expectations, with higher illness expectations and lower defensive optimism scores related to higher activity levels. In the longitudinal analyses ($N=57$), more positive illness expectations predicted lower activity levels at time 3, but expectations were not significant at time 2.

Recommendations for future work include examining the different effects of expectations and hopes, clarifying the role of uncertainty, testing an extended version of the Self-Regulatory Model that incorporates dispositional optimism, and developing novel interventions.

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PREFACE

The purpose of this thesis is to examine the role of expectations in the course of osteoarthritis (OA). The first two chapters review the literature on the clinical problem of OA and the application of expectations to health. Chapter 1 describes the diagnosis, aetiology, prevalence, economic impact, and the available treatment for OA. It then examines the impact of the condition upon individuals' psychological well-being. In chapter 2 the role of expectations in social cognition models is described with relevant literature reviewed, and the Self-Regulatory Model and illness representations introduced. The chapter then goes on to look at other applications of health-related expectations including optimism and possible selves.

The literature review highlights two major issues with previous expectations research: areas of study and methodological issues. The focus of expectations is generally on self-efficacy expectations (e.g. I am confident I can exercise regularly), outcome expectations (e.g. if I exercise then I will lose weight), and expectations of a specific treatment (e.g. my medication will relieve my pain), usually within a limited time frame. Aside from some components of illness representations little attention is given to individuals' expectations about how their condition will progress in the future and how this relates to outcomes such as physical function or exercise behaviour. Work on expectations in social cognition models usually examines these beliefs in relation to behavioural intentions, rather than actual behaviours. For example in the theory of planned behaviour the influence of outcome beliefs (i.e. expectations) is on attitudes, which form behavioural intentions, which then lead to

behaviour. There is little work on a more direct relationship between expectations and behaviour, particularly on exercise and activity levels.

The work described in this thesis aims to address these problems by examining how expectations affect exercise behaviour. The work is partly underpinned by the Self-Regulatory Model (SRM, Leventhal et al., 1980) as it includes individuals' representations of their knee OA and looks at expectations of timeline, consequences and cure/controllability. The thesis is also influenced by the Health Action Process Approach (HAPA, Schwarzer et al., 1992). Two theoretical constructs from this model are utilised; outcome expectations (individuals' expectations about the outcome of a specific behaviour) and self-efficacy expectations (the individuals' expectations about their ability to perform the specific behaviour). Whilst the thesis is guided by these models it also aims to be patient driven, so theory will be developed whilst being grounded in the patients' perspective. In order to achieve this, qualitative interviews are used and interpretative phenomenological analysis (IPA, Smith 1996) employed to analyse the data. This method has roots in phenomenology – i.e. it is interested in the individual's experience – whilst acknowledging the interpretative role of the researcher.

In terms of methodological issues, previous work on expectations has tended to be quantitative rather than qualitative, and several problems exist with instruments to measure expectations. Expectations questionnaires usually consist of one or two general items that may not cover all relevant areas of concern to patients, and as a result, may be less sensitive because they do not differentiate clearly between expectations of different areas, such as function and pain. Questionnaires on expectations are generally developed in an ad-hoc fashion; they are constructed

around what researchers or clinicians perceive as important and the measures are rarely piloted or tested for reliability and validity. Expectations are usually measured only at baseline in order to determine their influences on outcomes. As a result there has been little investigation into whether expectations of the condition change in relation to the improvement or deterioration of the condition over time, i.e. only the uni-directional influence rather than the bi-directional interaction is examined and so little is known about the stability of expectations. The time period in which the influence of expectations is studied is usually brief, particularly in relation to treatment expectations, therefore it is not clear how influential these beliefs are over a longer period of time, such as six months.

To date there has been little qualitative in-depth, exploratory work to examine why participants hold certain expectations and under what circumstances they change. Whilst there has been a considerable amount of work on expectations, the potential effects of expectations in non-surgical OA have been neglected. OA is a chronic condition where beliefs may have a large effect upon outcomes and self-management behaviour, and expectations may account for previously unexplained variance.

The use of qualitative approaches has increased in the last forty years, particularly since the groundbreaking work of the sociologists Glaser and Strauss, whose work with terminally ill patients led to the development of Grounded Theory (Glaser & Strauss, 1966; Glaser & Strauss, 1967). Qualitative methods can explore in more detail areas that are ignored in quantitative approaches, by asking “how” or “why” type questions, rather than “what” or “how many”. In addition, because quantitative methodologies are by their nature reductionist, much of the detail, richness and variability of the data that would be lost, is retained in qualitative interviewing. A

study by Donovan and Blake is an excellent example of the use of qualitative interviews (Donovan & Blake, 2000). They investigated doctors' reassurances to patients during rheumatology consultations and patients' subsequent interpretations. In a quantitative study the emphasis would have been on, for example, levels of satisfaction or reassurance of patients. This study provided information on *why* reassurance was not successful and how this aspect of the consultation could be improved.

Qualitative methods have, however, been strongly criticised, primarily because they are perceived to be lacking in reproducibility because of researcher bias, not scientifically rigorous (Mays & Pope, 1995), and unable to produce generalisable results due to the small sample sizes used. However, qualitative and quantitative approaches are different so cannot be judged using the same criteria and qualitative studies should still be conducted as rigorously as quantitative ones. Methods to ensure that qualitative approaches are more "scientific" include having interviews analysed by another individual to ensure agreement in coding, and openness (e.g. a detailed description of interviews with verbatim quotations, clear coding schemes and analysis) to allow readers to see how conclusions were reached (Mays & Pope, 1995). In addition, the aim of qualitative research is not to generalise, but to inform ideas about a subject and to gain in-depth information, and because of the time taken and the amount of data generated in interviews, it is unrealistic to expect researchers to interview a large sample.

Whilst qualitative methods are invaluable for exploring topics in detail and answering difficult questions, they cannot provide quantitative information on differences between groups, or on changes over time, or causal relationships, and

have difficulty dealing with large sample sizes. This is where quantitative methods can be used most effectively, and the thesis uses regression analysis to assess the influence of baseline predictors (including expectations) on self-reported activity levels longitudinally, and ANOVA to assess whether expectations and knee pain-related beliefs change across three timepoints.

In the light of the limitations identified in previous work, this thesis uses a mixture of qualitative and quantitative approaches to explore the area of expectations in chronic joint pain. The mixed methods approach suggested by Todd et al (2004) is used, in that it aims to use both quantitative and qualitative methods to answer different questions about the same phenomenon. Specifically, the use of a mixed methods approach allows the following: the development of a patient centred questionnaire using items generated by individuals with OA; the testing of the questionnaire in a cohort of OA patients using longitudinal analyses to look at changes over time; exploration of the subject of OA in detail with participants and in-depth exploration of how beliefs change over time.

Qualitative and quantitative approaches have traditionally been viewed as opponents because of their different foci; whilst quantitative methods aim to provide quantified answers to research questions, qualitative approaches aim to increase understanding of a phenomenon in natural settings and to give emphasis to meanings (Pope & Mays, 1995). Rather than viewing qualitative and quantitative approaches as being diametrically opposed due to their different emphases, they can be used to answer different questions, so should instead be seen as complementary (Pope & Mays, 1995). Recently, there has been an increase in the use of mixed methods, where different levels of the same phenomenon are investigated, and rather than asking the

same question, different methods can be used to answer different, but related, questions (Todd et al., 2004). Recent work by Yardley and Bishop (in press) has developed the concept of “composite analysis”, which is based upon pragmatic epistemology. They recommend the use of a variety of methods to understand complex processes; “it is possible to arrive at a richer and more complete description of a phenomenon than by using a single approach” (Yardley & Bishop, in press). Composite analysis acknowledges the problem of mixing methods from two different epistemologies and the need to keep their distinct characteristics separate in order to maximise their different contributions to the analysis.

Figure 1 outlines the study chapters and their relation to each other, with the qualitative studies informing the development of the questionnaire, and a sub-sample of participants from the cross-sectional study followed up in the longitudinal interviews. Findings from the systematic review also help to inform the checklist development and the methodology of the quantitative study.

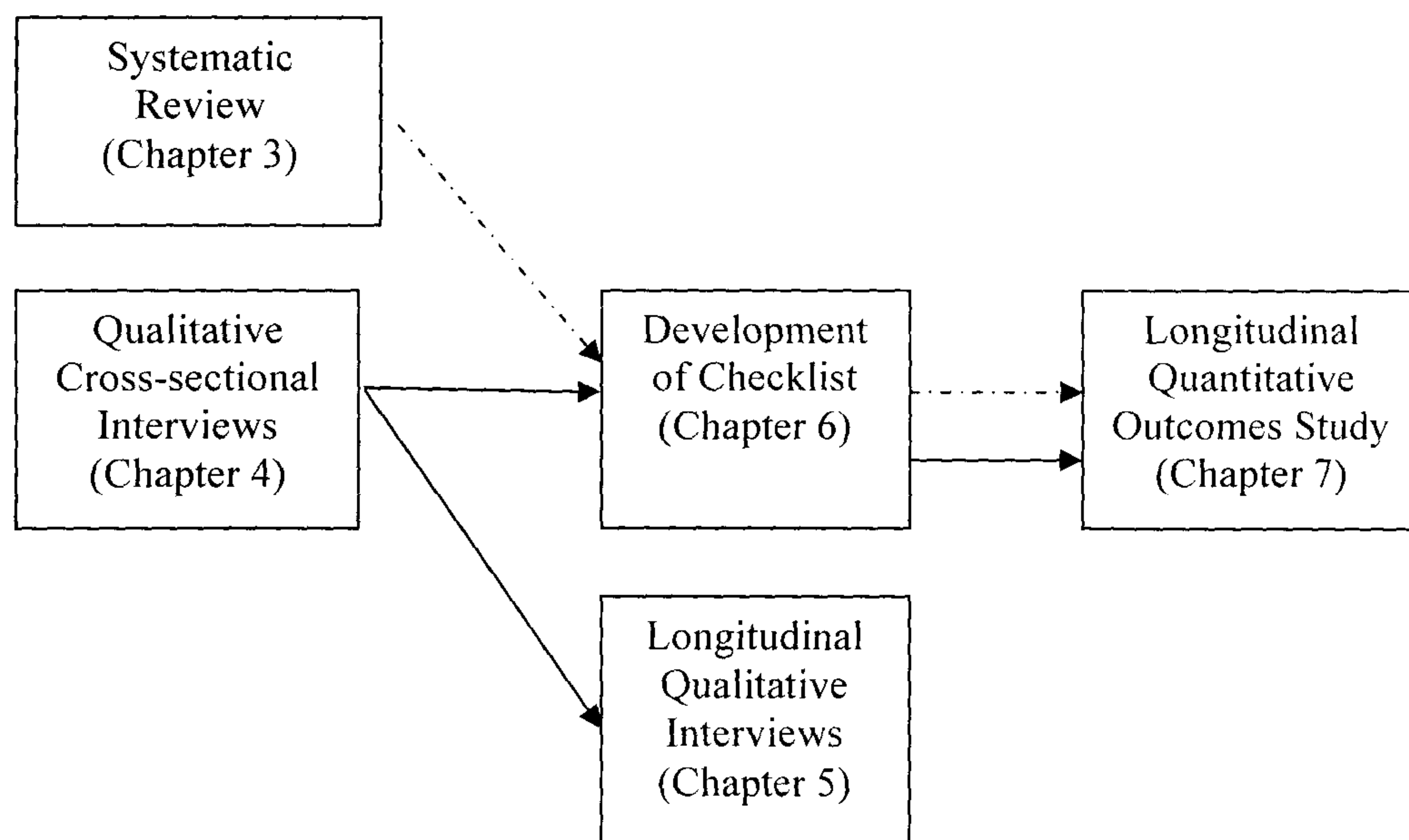


Figure 1 Outline of the study chapters

Chapter 3 is a systematic review of the influence of expectations on behaviour in chronic joint pain. Previous reviews have looked at expectations of treatment for back pain (Verbeek et al., 2004) and whether a predictive link exists between expectations and outcomes (Mondloch et al., 2001), but the review described in chapter 3 systematically examines the links between expectations and behaviour in chronic musculoskeletal joint pain of the back and lower limbs. The chapter aims to provide a more focused picture of the effects of expectations on behaviour in a specific condition, enable a better understanding of the role of expectations, and influence subsequent work including the measurement of expectations.

Chapter 4 is a cross-sectional qualitative study involving participants with knee OA. In-depth interviews will contribute to the body of qualitative work on expectations, of which there is currently only a small amount (Haas, 1999), particularly in relation to OA. The analysis of the data will focus on expectations and will provide participant derived, rather than researcher derived, items for the questionnaire described in chapter 6, relevant to this specific group of patients.

The longitudinal qualitative study described in chapter 5 develops the work of the previous chapter by looking at patient experiences and expectations at two time points, twelve months apart, allowing examination of whether expectations and aspects of the condition such as pain and function change. This is a longer time period than is normally used, and because OA is a condition which tends to change gradually, should provide a realistic picture. Chapters 4 and 5 both use qualitative methods in order to look at the meaning of the condition for individuals, and in chapter 5 participants are able to reflect back on expectations and perceived changes

in their condition to provide a more detailed examination of the phenomenon of living with OA on a day-to-day basis.

Most existing expectations questionnaires are researcher driven, ad-hoc measures that have no information about validity and reliability testing. However, following the generation of data from the qualitative interviews, chapter 6 describes the development and psychometric testing of a new questionnaire, the Knee Pain Beliefs Questionnaire (KPBQ), to produce a valid, reliable instrument that enables measurement of knee pain related beliefs in a systematic way. Factor analysis is also employed to establish whether items can be explained using a smaller number of underlying factors.

Chapter 7 describes a study that uses the questionnaire developed in chapter 6 to measure patients' expectations and other beliefs related to knee pain longitudinally. Expectations are usually measured at baseline and then related to outcome variables, neglecting the possibility that expectations themselves may change over time. By measuring expectations longitudinally this issue can be addressed. The study also allows examination of the relationship between expectations and behaviour in the form of self-reported exercise.

When using mixed methods it is important to identify which method is given priority, and be clear when the findings will be integrated (Creswell et al., 2004). In this thesis, qualitative and quantitative methods will be given equal priority; detailed data collection and analysis is provided for both methods, and whilst the cross-sectional qualitative data are used to inform the quantitative study through development of the questionnaire, the data are also analysed in detail to form

separate studies. The main integration of the findings occurs in the development of the questionnaire, but also in chapter 8, where the findings of all of the studies are discussed together to inform future work.

In summary, this thesis has several broad aims:

1. To assimilate and systematically review previous research conducted on the relationship between expectations and behaviour in back and lower limb musculoskeletal pain.
2. To explore the phenomenon of knee OA and patient expectations in order to gain a clearer understanding of their beliefs, and to generate items for a patient-derived expectations measure.
3. To look at expectations longitudinally, including how patients' ideas change in relation to changes in the condition.
4. To test the reliability and validity of a new knee pain expectations questionnaire.
5. To use the new questionnaire in a longitudinal study in patients with knee OA to examine the effects of expectations on behaviour and whether expectations change over time.

CHAPTER 1: OSTEOARTHRITIS (OA)

1.1 THE CLINICAL PROBLEM OF OA

1.1.1 Symptoms

Musculoskeletal disorders are amongst the most widely reported health problems within the general population, and within this group of disorders osteoarthritis is the most common (Badley et al., 1994). OA is a chronic, localised degenerative condition of the joints, with destruction of the cartilage and subchondral thickening of the bone.

Pain is the primary symptom reported in patients with OA, and is generally a gradual onset of aching, although movement can produce sharp, “shooting” pains, also described as a burning sensation. In the lower limb, pain often increases on weight-bearing, and the degree and frequency to which pain occurs varies between individuals and in each individual over time. Pain is frequently reported at rest or during the night, disturbing sleep, and it is hypothesised that this tiredness increases the perception of pain (Drewes & Arendt-Nielsen, 2001). Because the articular cartilage contains no nerve endings the origin of the pain may be unclear and pain may also be referred from one site to another, for example from the knee to the hip.

Joint stiffness and functional disability are also common problems in OA; stiffness tends to be worst after periods of rest, particularly in the morning following sleep, although it rarely lasts for more than 30 minutes. Functional disability is particularly problematic in weight-bearing activities such as walking and climbing stairs. The problems experienced by individuals with OA can lead to a vicious circle of increased pain, stiffness and reduced physical functioning.

1.1.2 Diagnosis

No definitive diagnostic or gold standard tests exist for OA so a differential diagnosis is made using clinical examination and radiological findings. On examination OA is indicated by pain, crepitus (i.e. ‘creaking’ or ‘cracking’), stiffness, restricted movement, bony enlargements and in some cases inflammation and tenderness (Hochberg et al., 1995). Damage to the joint is indicated on a radiograph by joint space narrowing between the femur and tibia or femur and patella (due to erosion of cartilage), the presence of osteophytes (bony growths on the edge of the bone), and sclerosis (hardening of the bone) (Kellgren & Lawrence, 1957).

Because symptoms may vary the most sensitive and specific combination of classification criteria for OA of the knee, using clinical and radiographic evidence has been found to be knee pain, osteophytes, and one of the following: morning stiffness of up to 30 minutes duration; age 50 years and over; crepitus on active motion (Altman et al., 1986). When using just clinical criteria alone, the presence of knee pain and at least three of the following is required: age 50 years and over; stiffness of up to 30 minutes; crepitus; bony tenderness; bony enlargements; no palpable warmth (Altman et al., 1986).

1.1.3 Subtypes of OA

OA is increasingly seen as several similar disorders with the same outcome; a damaged joint that causes pain and disability. It is increasingly viewed as a process that the joint undergoes in response to trauma and some of these changes are adaptive, some maladaptive. One of the major distinctions made between subtypes

of OA is whether it is primary or secondary. OA is defined as primary, or idiopathic, if no other obvious cause exists, whilst secondary OA is diagnosed in cases where there are identifiable causes such as previous injury to the joint. The prognosis for OA is variable and outcome is dependent on multiple factors, including obesity and genetics (Sharma et al., 2000; Peach et al., 2005).

1.2 AETIOLOGY

OA usually develops over many years and as a result may have a multifactorial aetiology. Proposed risk factors include obesity, mechanical “wear and tear”, occupation, physical activity, injury, muscle involvement, genetic factors, ethnicity and hormonal influences.

1.2.1 Body Weight

The role of excess body weight plays a significant role in the development of lower limb OA, particularly in women (Felson et al., 1988; Spector et al., 1994). Despite strong evidence for the role of obesity in OA, the exact processes by which obesity “causes” OA are unclear. The correlation between body mass index (BMI) and radiographic severity in patients with varus deformities weakens once malalignment of the joint is controlled for, suggesting that malalignment may be a mediating factor in the link between joint damage and BMI (Sharma et al., 2000). Interestingly, this decrease in correlations did not apply to those with valgus deformities, supporting the hypothesis that OA is a set of heterogeneous conditions with similar outcomes.

1.2.2 Mechanical Use and Abuse

Due to the perception that OA is caused by mechanical “wear and tear” to joints, occupation and physical activity have been widely investigated as possible causes. People, particularly men, with occupations involving kneeling and squatting, heavy lifting, or a combination of these, were found to have the highest prevalence of symptomatic and radiographic OA (Felson et al., 1991; Coggon et al., 2000). This gender bias may, however, be due to a higher percentage of men carrying out these types of jobs. When the association between occupation and knee pain was examined separately for men and women, carpenter, miner and construction worker were most closely associated with knee pain for men; for women it was sales assistant, nurse and machinist, reflecting gender differences in occupations (O'Reilly et al., 2000).

Elite sportsmen have been found to have an increased prevalence of OA (Deacon et al., 1997), which may be due to their increased risk of injuries. However, no association has been found in amateur sportsmen or individuals involved in regular physical activity (Sutton et al., 2001), and knee injuries have been proposed as a more important contributory factor than general physical activity (Gelber et al., 2000).

1.2.3 Muscle Involvement

Despite OA being a problem that primarily concerns the cartilage, a burgeoning body of work suggests the quadriceps muscles of the thigh play an important role in disease progression, and that increased weakness in these muscles is associated with increased pain and disability (Fisher et al., 1991; Hurley, 1999). A decrease in muscle function was found to be most pronounced in the “long” muscles that

perform functions such as climbing stairs, rising from a chair and walking (Fisher et al., 1991; Fisher et al., 1997; Fisher & Pendergast, 1994), which may explain the increase in functional disability found in OA patients.

To determine whether muscle weakness is a cause of disease progression, or a result of it, a “normal” population (no radiographic changes and no symptoms), asymptomatic OA (radiographic changes only) and symptomatic patients were compared (Slemenda et al., 1997). Significant differences in muscle strength were found; unsurprisingly those with OA were significantly weaker on knee extension than people with no knee problems and those with pain were weaker than those with radiographic damage alone. Crucially, asymptomatic patients were weaker than those with no changes, suggesting that muscle weakness precedes knee pain and disability.

1.2.4 Genetics

Some evidence exists for a genetic influence in OA. In monzygotic (MZ) and dizygotic (DZ) female twin pairs the proportion of variance accounted for by genetic factors in hand and knee OA ranged from 39% (knee osteophytes and narrowing) to 65% (osteophytes at all sites) after adjustment for age and weight (Spector et al., 1996). Comparison of male and female MZ and DZ twin pairs found a strong genetic influence in women, but not men (Kaprio et al., 1996). These studies suggest that genetic factors may be particularly influential in generalised OA and in females.

Classic twin studies assume that any difference in rates between MZ and DZ twins is due to shared genes in the MZ group. However, it is possible that MZ twins also share a more similar environment than DZ twins, increasing concordance. This may

extend to the foetal environment, as a subset of MZ twins share a common placenta and therefore a more similar nutritional environment (Phillips, 1993).

1.2.5 Ethnicity

The majority of the small amount of work on ethnic group differences has been cross cultural, comparing populations from different countries. However, the HANES I study compared black and white participants from the same U.S. population and found black women to have a significantly higher risk of radiographic OA than either white men or women (there was a nonsignificant trend for an increased risk in black men). This increased risk persisted even when other factors (such as BMI) had been controlled for (Anderson & Felson, 1988).

1.2.6 Hormones

It has been hypothesised that oestrogen plays a role in OA, due to the increased prevalence in women over the age of fifty, around the time of the menopause. A protective effect of hormone replacement therapy (HRT) has been found in a number of studies (Wluka et al., 2000), and may be particularly effective in large, rather than small, joints (Spector et al., 1997), but no effects have been found in radiological OA (Richette et al., 2003).

1.3 PREVALENCE

To determine estimates of the prevalence of OA in epidemiological studies radiographic evidence is usually favoured as it is objective and can be standardised. However, radiographic damage often bears little relation to symptoms, partly because the cartilage of the knee joint is not innervated; in one study 16% of

participants showed definite radiographic changes indicative of OA, but only 40% of this sub-group had knee pain symptoms (Felson et al., 1987). Conversely, in a survey of primary care patients 46% of individuals with knee pain had no radiographic damage, whilst 17% of asymptomatic participants showed radiographic changes (McAlindon et al., 1992b). This disparity has led to the recognition of two separate syndromes: clinical osteoarthritis and radiographic osteoarthritis.

Because of this disparity between radiographic changes and symptoms, some studies have preferred to employ self-reporting of symptoms, usually pain, and a prevalence of approximately 25% of participants reporting pain has consistently been found (Jinks et al., 2004; O'Reilly et al., 1996; McAlindon et al., 1992a). A significant gender difference also exists, with women more likely to report symptoms of knee pain than men (Felson et al., 1987; McAlindon et al., 1992a).

When comparing prevalence rates across studies, the question used should be considered. When O'Reilly et al asked patients about pain on most days during the last month their results were similar to those of McAlindon et al (O'Reilly et al., 1996; McAlindon et al., 1992a). When they asked participants how often they had experienced pain in the last month (the ACR criteria), the prevalence rate was lower (19%).

1.4 COSTS ATTRIBUTABLE TO OA

Due to its prevalence and chronic nature, management of OA is expensive, both for health care providers and individuals with OA. Expenditure can be divided into direct costs for medical services, such as GP consultations and prescriptions, and

indirect costs, which includes absences from work and home care costs. In 2000 there were over three million GP consultations and 114,628 hospital admissions for OA in Britain, and 33.5 million prescriptions were written for drugs related to arthritis, with costs totalling £327 million (Arthritis Research Campaign, 2002).

With regard to indirect costs 36 million working days were lost in 1999-2000 (Arthritis Research Campaign, 2002), a surprisingly high figure considering that OA is a condition affecting mainly older people. It is also estimated that in 2001 £43 million and £215 million were spent on community and social services for OA respectively (Arthritis Research Campaign, 2002), and £2.42 billion were spent on people claiming incapacity benefit because of arthritis and related conditions in the same year (Arthritis Research Campaign, 2002).

However, interpreting economic estimates is problematic. Separate health cost figures are not available for England, Wales, Scotland and Northern Ireland so regional patterns cannot be determined. Problems also exist in the way the condition is classified as figures may be produced for separate types of arthritis, or counted as one condition. This yields a somewhat distorted picture due to differences between conditions such as Rheumatoid Arthritis (RA) and OA; RA patients require more expensive treatment with more hospital visits and are usually younger than those with OA, so are more likely to be employed and therefore may take more days of sick leave or receive more in benefits. However, RA is a much less prevalent condition than OA, so the overall cost is less. Caution must also be used when interpreting results in general as iatrogenic side effects such as gastro-intestinal complaints may increase the reporting of OA-related problems but are often not controlled for (Lee et al., 2001).

1.5 TREATMENT OF OA

Due to its chronic nature the main aims of treatment in OA are to reduce pain and stiffness and to maintain or increase function, mobility and health-related quality of life. Various management regimens attempt to alleviate the symptoms of OA and these can be roughly divided into; pharmaceuticals, nutraceuticals, non-pharmaceutical interventions, and surgical interventions. A recent report recommended a combination of pharmacological and non-pharmacological interventions for optimal treatment (Jordan et al., 2003).

1.5.1 Pharmaceuticals and Nutraceuticals

Paracetamol is recommended as the first-line drug, with the dose increasing to a maximum of 4 grammes per day, where necessary (Hochberg et al., 1995). If this is ineffective a stronger analgesic, such as co-codamol (codeine and paracetamol) should be prescribed. If pain levels are still uncontrolled, the analgesic can either be altered to a non-steroidal anti-inflammatory drug (NSAID) or taken in conjunction with a NSAID. Unfortunately analgesics and NSAIDs only have limited success and not all patients are able to tolerate them, reporting problems such as stomach upsets. NSAIDs are also potentially harmful as they can increase the risk of gastro-intestinal (GI) bleeding in older people. Cox-2-specific inhibitors can reduce the risk of an upper GI event compared to an NSAID (Bombardier et al., 2000), and are prescribed in patients particularly susceptible to upper GI bleeding. Alternatively, topical preparations can be considered, and good evidence exists for their efficacy in chronic conditions (Moore et al., 1998a).

Nutraceuticals have become increasingly popular in recent years, with glucosamine sulphate and chondroitin sulphate being widely used. Use of these

substances is based on the premise that they could increase formation and regeneration of cartilage, which is promoted by naturally occurring glucosamine and chondroitin found in the cartilage matrix and synovial fluid of the joint (Hauselmann, 2001). In two meta-analyses beneficial effects were found in OA patients for both glucosamine and chondroitin on pain, functional impairment, mobility and joint space narrowing (Richy et al., 2003), along with few adverse events (McAlindon et al., 2000). There is also evidence that benefits increase the longer supplements are taken (McAlindon et al., 2000), with positive effects seen at three years (Pavelka et al., 2002; Reginster et al., 2001).

Much of the research on nutraceuticals has been hampered by poor methodology including small sample sizes, short treatment periods and inconsistency in outcome measures used. There is also evidence of publication bias (McAlindon et al., 2000; Richy et al., 2003) and many studies, particularly early ones, were funded by the producers of supplements, questioning their objectivity. The minimum required daily dose, its precise actions in the joint and whether supplements are more beneficial for those with mild or severe OA, are also unclear. However, recent work indicates that a combination of glucosamine and chondroitin may have a greater effect in patients with moderate to severe pain (Clegg et al., 2006).

1.5.2 Exercise

Because of the possibility of side-effects and the lack of efficacy of some medications there is an increasing interest in the use of non-pharmacological interventions, which have been recommended as an integral part of the management of OA (2000), the most popular being exercise. Weakness of the quadriceps muscles

of the thigh has been identified as a common problem in knee pain and so the majority of exercise programmes target these muscles. They also aim to improve overall aerobic fitness, which is compromised in people with OA (Minor et al., 1988).

Where OA patients participated in sustained and intensive programmes of strengthening exercises, improvements were seen in strength, walking time, pain, functional performance, difficulty and dependence (Fisher et al., 1991) and in systolic blood pressure and submaximal heart rate, suggesting that strengthening exercises have a beneficial effect on aerobic capacity (Fisher & Pendergast, 1994). However, these studies used small groups of participants with no controls and no follow-up assessments meant that participants' exercise levels following the programme could not be measured.

To examine the effects of different types of exercise, a randomised controlled trial (RCT) compared aerobic exercise and resistance exercises against a control group (who received a health education programme and telephone contact only) over 18 months (3 months supervised, and 15 months home exercises) (Ettinger, Jr. et al., 1997). Both interventions were significantly more effective with regards to reducing self-reported disability, pain and walking time, with the aerobic group experiencing greatest improvements. The aerobic group also showed the greatest improvements in depressive symptomatology, even after controlling for changes in pain and disability, and after separating out high and low depressive symptomatology (Penninx et al., 2002). However, no follow-up data were collected so it is unclear how long the beneficial effects lasted and the intervention's duration of 18 months was not clinically practicable.

Where OA patients were randomised to receive either standard GP treatment (medication and advice where necessary) or treatment from a primary care physiotherapist, moderate and small effects were found for pain and observed disability respectively for the intervention group, but no effect for NSAID use (van Baar et al., 1998). The improvement in pain persisted at six months follow-up, but had disappeared by nine months. Although the studies by both Ettinger and van Baar were methodologically strong (i.e. appropriate randomisation methods, blinded assessors and GPs, stated power calculations and adequately powered), the effects of medication were not controlled for, which is a common problem in many exercise studies.

Home-based exercise interventions are clinically practicable, requiring minimal interventions from healthcare professionals and minimal use of resources. In an examination of the effects of home-based exercises, benefits were found for pain and physical function, with small treatment effects for function still evident at two years (Thomas et al., 2002). The exercise groups had significantly lower pain at each assessment period with small effect sizes and a small treatment effect was found for physical function at the two-year assessment. Short-term benefits were also seen in a study of a progressive exercise regimen (Petrella & Bartha, 2000), and a walking intervention (Kovar et al., 1992).

In addition to content, intensity and location of the intervention, the method of delivery (e.g. in a group setting or on a one-to-one basis) may be an important factor. Participants receiving individual attention with more dedicated time may be expected to show the greatest improvement. Alternatively, being part of a group,

with the mutual support and encouragement that it provides, may produce greater improvements. However, in comparisons of group and individual interventions little difference has been found in either self-report or objective measures (Hurley et al., 2007; Fransen et al., 2001).

Whilst the benefits of exercise for knee OA have been demonstrated, much of this research has methodological flaws. Studies are often small, under-powered with short follow-up periods, and do not classify patients in terms of severity of the pain, which might help ascertain when during the course of the condition exercise is most beneficial. Whilst under supervision levels of exercise can be monitored, but following discharge or for home-based programmes, the amount of exercise performed is at the individual's discretion, so closer examination of participants' adherence levels and changes in their activity following an intervention may also be required. Differences in adherence may explain small effect sizes and evidence of a dose-response effect was seen in the home-based exercise study (Thomas et al., 2002).

1.5.3 Other Non-pharmaceutical Interventions

1.5.3.1 Hydrotherapy

Hydrotherapy, where exercises are performed in heated pools, is hypothesised to be a beneficial intervention for musculoskeletal disorders due to a combination of several factors: increased sensory input from turbulence, pressure and temperature of the water; muscle relaxation, which is attributed to the warm temperature and buoyancy; decreased joint compression and increased mental and physical stimulation, which serve as a distraction from the pain (Belza et al., 2002). However, there have been mixed findings in the few studies that have evaluated the use of

hydrotherapy in OA (Green et al., 1993; Patrick et al., 2001), and participants with high adherence reported higher health status scores and less depression compared to non-adherent and control participants (Belza et al., 2002). Although direct costs may decrease, this may not compensate for the high costs associated with hydrotherapy (Patrick et al., 2001).

Although hydrotherapy is a popular treatment and can be beneficial, it requires a significant investment, both financially and in terms of patient time and effort. The existing evidence suggests that it does not deliver sufficient benefits to justify wide implementation when other interventions may be at least as equally as effective.

1.5.3.2 Weight Reduction

Because obesity has been found to be strongly related to knee OA, weight loss may be an effective intervention. In a longitudinal, retrospective study, weight loss in women with a BMI of 25 or more was found to significantly reduce the risk of developing symptomatic knee OA over a ten year period (Felson et al., 1992). In comparisons of different interventions, combinations of diet and other modalities produced the best outcomes for walking time and self-reported physical health (Rejeski et al., 2002), and pain, functional disability, walking time and weight loss (Huang et al., 2000).

Encouraging overweight individuals to follow a combined exercise and weight reduction programme in conjunction with other methods could have significant health benefits for their knee problems and other health conditions associated with obesity.

1.5.3.3 Acupuncture

Acupuncture is regularly used to alleviate pain and improve function, but much of the evidence comes from clinical reports and few studies have been conducted in OA. Improvements have been seen in pain levels and NSAID use (the greatest improvements were seen in those with shorter disease duration) (Christensen et al., 1992), and in self-reported disability (Berman et al., 1999). However, the possibility of a placebo effect occurring simply through the intervention group receiving treatment was not controlled for, and indeed no significant differences were found when sham and real acupuncture were compared (Takeda & Wessel, 1994).

To date, studies that have looked at the use of acupuncture in OA have produced mixed results, which may be due to a placebo effect, and also because therapists cannot be blinded to treatment, thereby subtly influencing patient responses.

1.5.3.4 Orthoses

Medial compartment OA is the most common type of the condition and clinical reports suggest that insertion of a lateral heel wedge into shoes shifts the forces travelling down the leg away from the medial side, breaking the cycle of varus deformity and increased pressure on the medial side. Some benefits of using orthoses have been seen, including pain reduction (Toda et al., 2001), regardless of radiographic severity (Keating et al., 1993), and functional improvement (Fang et al., 2006). However, other studies found no differences where radiographic OA was most severe (Sasaki & Yasuda, 1987), or between insole shapes on walking speed, stride length or cadence (Kerrigan et al., 2002). A major problem with research on

orthoses is the lack of control group so how the use of insoles compares to no insole is not clear.

To gain a more accurate picture of the benefits of insoles a large, controlled, randomised study over a prolonged period of time is required, using both objective and subjective measures, which controls for medication use and measures adherence.

1.5.4 Joint Replacement

For patients with severe pain and impaired function, and where other treatments have provided no relief, joint replacement may be considered either for all, or part, of the joint, depending on the extent of the damage. There is good evidence for the procedure's efficacy and improvements are generally seen in pain levels and global functioning (Callahan et al., 1995). However, despite the benefits, patients may be reluctant to undergo joint replacement for many reasons, including beliefs about the level of pain and disability required to be "suitable" for the operation, fears about the procedure and outcome and concerns about caring for their self whilst recuperating (Hudak et al., 2002; Figaro et al., 2004).

1.6 PSYCHOSOCIAL FACTORS AND OA

1.6.1 General Psychosocial Impact

Because OA is a chronic condition that produces specific problems of pain and functional limitations, there has been a great deal of interest in the psychological and behavioural impact OA has, both in the way in which individuals react to it and the outcomes that these reactions produce. OA-related pain in the knee was shown to

have direct effects in the expected direction on physical and social functioning, depressive symptoms and perceived health with no mediating effects of function between pain and depression (Bookwala et al., 2003).

In a comparison of psychological variables across several conditions, individuals with OA were found to have increased depression and anxiety and decreased mastery (a belief of influence over, for example, OA), compared to individuals with cardiac disease, diabetes, stroke, cancer, lung disease and atherosclerosis (Penninx et al., 1996). These findings are surprising since it could be intuitively assumed that life-threatening conditions such as cancer and lung disease would have far greater impact on anxiety and depression levels, particularly in terms of perceived possible mortality. However, more severe conditions are generally accompanied by good support systems and are acknowledged as being serious and threatening, which may not be the case for OA.

Most people with OA are not referred to secondary care, but are managed in the community by their GP, who may underestimate the impact of the condition. In a comparison of GP and patient views of their condition, patients rated their functional disability as more severe, and agreement of functional disability, depression and anxiety levels between patients and GPs were low (Memel et al., 2000). These perceptions held by the GPs may have a significant impact on the way in which patients' conditions are managed and may partially explain why so few patients with OA are referred to secondary care.

1.6.2 Psychosocial Predictors of OA-related Outcome

The previous section examined the impact that OA, and particularly its associated pain, can have on individuals; this section looks at how psychosocial factors can impact upon OA-related outcomes such as pain and functioning over and above objective measures. In terms of the psychosocial impact on pain symptoms, state anxiety and learned resourcefulness accounted for 15% of the variances in total pain scores, whilst a combination of depression, state anxiety and trait anxiety accounted for 32% of variance in present pain intensity. Objective indices of damage from radiographs were not significant predictors of pain but more severe damage did predict more functional disability (Summers et al., 1988)

Helplessness is an explanatory style (how an individual interprets an event), and is the belief that, as a result of past events, an individual's own behaviour will have no effect on future events, so unwanted occurrences such as pain are perceived as uncontrollable (Peterson & Seligman, 1987). In OA patients helplessness was strongly related to pain severity reporting, using three different measures of pain (Creamer et al., 1999), and accounted for significant variance in self-reported functional disability; as helplessness increased, disability increased. Along with objective radiographic measures, pain severity and BMI, helplessness accounted for 60% of variance in disability scores. (Creamer et al., 2000). Although the majority of studies on helplessness have been on Western populations, higher levels of helplessness were significantly related to worse physical function in Asian patients in Singapore (but not to bodily pain) (Thumboo et al., 2002). Helplessness was the only psychosocial variable used in this study, so the relationship with, for example, depression and anxiety is not known.

Self-efficacy can be defined as an individual's perceived ability to carry out a task (Bandura, 1977) and has been widely investigated in OA patients because of the importance of self-management. Self-efficacy is situation-specific, therefore an individual's perceived self-efficacy for exercising twice a week may differ from their self-efficacy for following a healthy diet (Schwarzer & Fuchs, 1995). In baseline data on knee OA, patients' self-efficacy was positively related to speed on stair climbing and lifting and carrying tasks, and both self-efficacy and knee pain explained a significant amount of variance for both objective and self-reported physical disabilities (Rejeski et al., 1996). At 18 months follow-up, baseline adjusted self-efficacy scores were compared across three groups: aerobic exercise, conditioning exercise and education control (Rejeski et al., 1998). The two exercise groups had higher self-efficacy scores compared to the control group, but when knee pain and self-efficacy scores were controlled for, treatment group was no longer significant. Knee pain and self-efficacy scores were independent predictors of time taken to climb stairs, a function that is particularly problematic in this patient population; higher self-efficacy predicted quicker stair-climbing.

Catastrophising is the tendency to focus on and exaggerate the threat of painful stimuli and negatively evaluate one's ability to deal with pain (Rosenstiel & Keefe, 1983). Evidence exists that catastrophising is related to pain-reporting, pain-related disability, distress and joint tenderness in rheumatological conditions (Edwards et al., 2006), and is also related to pain intensity, disability and psychological distress in chronic musculoskeletal conditions, even when physical impairment is controlled for (Severeijns et al., 2001). Catastrophising has also been examined as a mediator of gender on pain related outcomes. In a study of 168 individuals with knee OA (72 men), women who had catastrophising thoughts were most likely to have higher

levels of pain, a relationship that held even when depression scores were controlled for (Keefe et al., 2000). Women were also found to report higher pain and disability levels, and exhibit more pain behaviour than men.

1.6.3 Psychosocial Interventions

The relationship between psychological aspects and arthritis suggests the potential importance of psychological factors and that modifying patient beliefs may improve outcomes. In a recent meta-analysis on interventions for managing arthritis-related pain, a range of psychosocial interventions were included, the majority of which were cognitive-behavioural (Dixon et al, 2007). Participants who received psychosocial interventions reported significantly lower levels of pain, as well as anxiety, depression, physical disability and higher levels of active coping. These findings support the effectiveness of psychological interventions in modifying beliefs and improving psychological and physical outcomes.

1.6.4 Methodological Issues

Although a number of studies have been conducted to look at the interaction between OA and psychosocial variables, poor methodology can leave them open to over- or under-estimation of the true extent of the relationship between variables.

1.6.4.1 Design

The use of cross-sectional designs makes the direction of influence difficult to determine, for example it is not apparent whether an individual is depressed because they have a high level of pain, or pain levels are elevated due to depressed mood. Longitudinal studies are required in order to reveal the direction of causality, and the effects that changes in a condition can have on psychosocial aspects. Small,

convenience samples are often used, reducing the generalisability of findings.

Interactions between different psychological aspects, such as helplessness and depression, may also occur and need to be controlled for, otherwise inflated results suggesting significant relationships between OA and psychosocial variables may be produced.

1.6.4.2 Instruments

The instrument selected to measure variables is a potential source of bias.

Significant correlations were found between three pain measures (WOMAC, the McGill pain questionnaire (MPQ), a pain visual analogue scale (VAS)), indicating that they measured the same concept. However, significant associations were also found between depression, anxiety and fatigue measures and the McGill, but not the VAS or the WOMAC (Creamer et al., 1999). The authors suggest the MPQ measures anxiety and depression directly, and so may increase the association between pain and these psychosocial variables. This possible overlap needs to be considered when selecting appropriate outcome measures and interpreting results.

1.6.4.3 Sample Selection

Many studies on psychosocial factors in arthritis have either focused purely on RA patients or have used mixed samples of RA and OA patients, where the data are not analysed separately. Although they are both rheumatological conditions that produce pain and functional disability, they affect different age groups, have different treatment regimens, different physical and psychosocial effects, and different coping strategies. OA is also often seen as a natural part of the ageing process, therefore the degree to which findings are generalisable to each other is questionable. Studies that

look exclusively at OA patients will enable the true impact of the condition to be assessed.

1.6.4.4 Disease Duration and Severity

Variation may be introduced through differences in disease duration and severity.

When OA patients were divided into chronic, episodic, sporadic, and no pain groups, those with more chronic pain had decreased quality of life (Hopman-Rock et al., 1997), and more physical and psychosocial disability (Hopman-Rock et al., 1996) compared to those with sporadic or no pain.

In a comparison of patients with chronic arthritis or vision conditions (those who had had two or more illness downturns in the previous 10 months) with those who were newly diagnosed (no problems in the previous 10 months), chronic arthritis patients reported the greatest psychological distress, least well-being and greatest pain levels, suggesting an additive effect of the disease, rather than an increase in adjustment. In addition those whose symptoms were more frequent and of a longer duration had less well-being and greater distress compared to those with new problems (Erdal & Zautra, 1995). Unfortunately no information was provided on the types of arthritis that participants had, making it difficult to establish how applicable the findings are to OA.

1.7 SUMMARY

OA is a condition that causes pain, stiffness, reduced functioning and psychosocial problems, and because it is an age-related condition it places a huge burden on the health-care system. As there is no cure, palliative treatment is required to reduce pain and maintain independence. Pharmaceuticals are not always effective and may

cause harmful and unpleasant side effects, whilst there is still a lack of evidence for the benefits of nutraceuticals. Health-care providers are increasingly turning towards non-pharmaceutical interventions; particularly exercise as it is non-invasive, can improve aerobic capacity and has psychological benefits.

CHAPTER 2: EXPECTATIONS

This chapter looks specifically at expectations, associated constructs that have used beliefs about the future, and their role in health-related behaviour. The first section outlines and evaluates the most commonly used health behaviour models and highlights the expectations components. Where available, meta-analyses and systematic reviews are included to highlight the strengths and weaknesses of the models, along with relevant individual studies that are judged to be of a high quality or which illustrate a particular point. The following section discusses work on applied approaches that have used expectations in health settings and introduces concepts related to expectations, such as optimism and pessimism.

2.1 EXPECTATIONS AND HEALTH BEHAVIOUR MODELS

Expectations have been utilised, in various forms, in cognition and social cognition models to explain variation in individuals' behaviours. These models have their origins in the expectancy-value approach, which states that a behaviour or a behavioural intention is the result of the probability of an outcome and the value attached to that outcome (see figure 2.1 for an example) (Edwards, 1954).

2.1.1 The Health Belief Model

The Health Belief Model (HBM) (figure 2.2) (Rosenstock, 1966) was originally developed to predict preventive behaviours such as screening programme attendance (Orbell et al., 1996) and influenza vaccination uptake (Cummings et al., 1979), but has also been used to explain variance in existing conditions such as diabetes (Bradley et al., 1987).

The HBM distinguishes between *outcome* expectations (expectations for the outcome of performing a behaviour) in the form of evaluations of benefits and threat or cost, and *risk* expectations in the form of susceptibility and severity beliefs (for example expectations regarding the risk of having a heart attack or developing cancer), and their perceived seriousness.



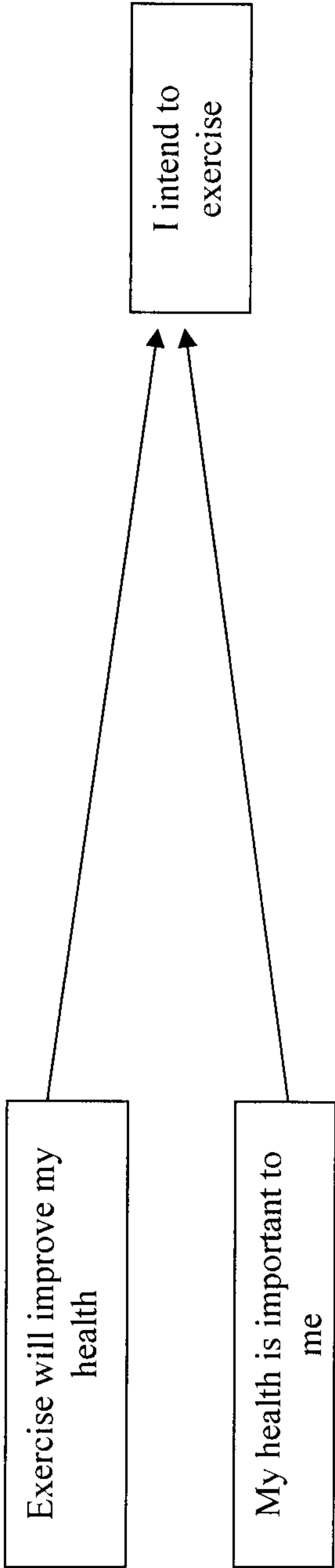


Figure 2.1 Expectancy-value Model (Edwards, 1954)

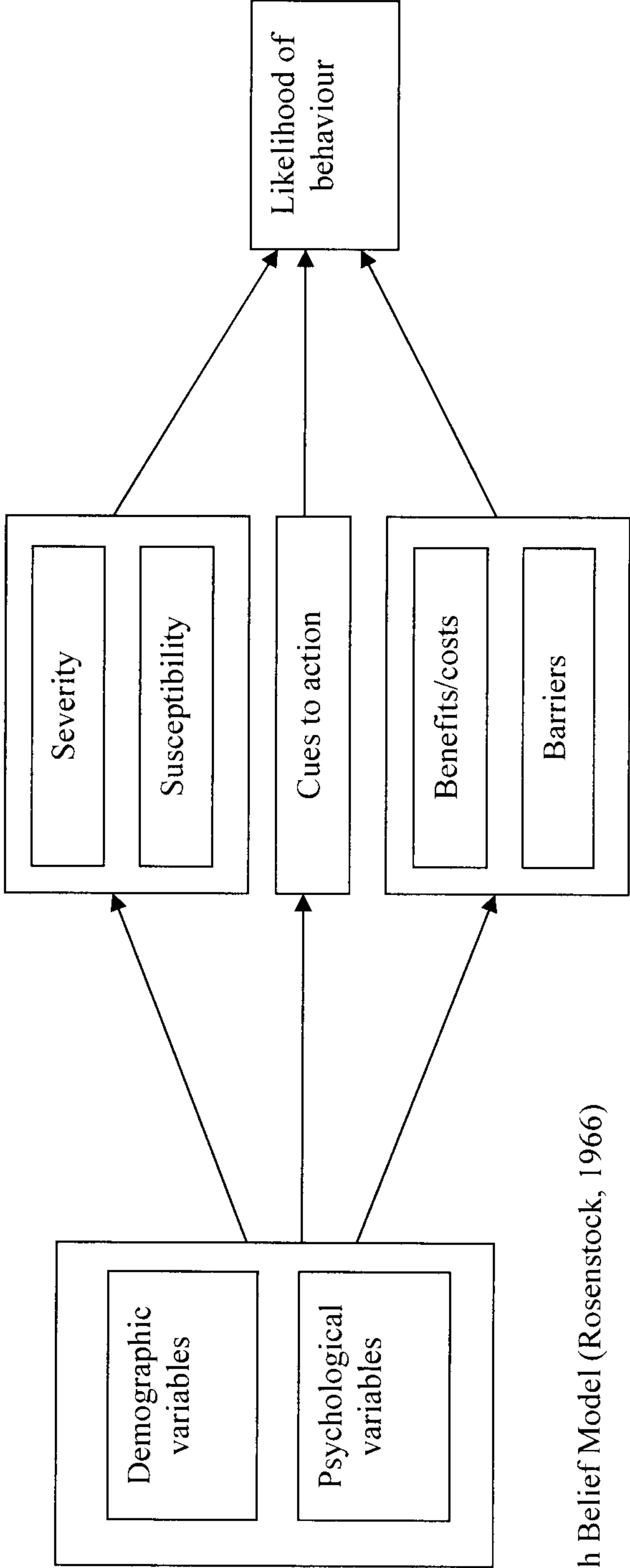


Figure 2.2 Health Belief Model (Rosenstock, 1966)

The HBM has been applied to a wide variety of health behaviours, with variation in the model's predictive validity and the importance of the individual components in predicting behaviour. For attendance at breast self-examination classes, perceived susceptibility was the best discriminator (Calnan, 1984), whilst perceived benefits predicted uptake of flu vaccinations (Cummings et al., 1979). Possible reasons for the large variations include the huge range of conditions studied, the wide variety of operationalizations of susceptibility (including “probability”, “possibility”, “likelihood”) (Becker & Maiman, 1975), the definition of perceived barriers, which were originally defined as psychological but have subsequently been classified as either psychological or physical, and the levels of severity. For example, many people would perceive breast cancer as more severe than ‘flu so would be expected to react to the threat of breast cancer differently to that of a bout of ‘flu.

Despite its importance as an early model of behaviour, the HBM has been widely criticised because the original model had no role for self-efficacy expectations, it is a purely cognitive model with no role for social and emotional factors and there is no distinction between contemplation and action (Schwarzer et al., 1992). Moreover, no specification is provided for how the components should be combined, or how the different elements interact with each other (Quine et al., 2001). Furthermore, the predictive validity of individual components has been questioned. In a meta-analysis, individual components of the model accounted for only small amounts of variance in behaviour and the heterogeneity of effect sizes suggested that the studies were measuring different underlying constructs (Harrison et al., 1992). Alternatively this may have been due to variations in the study design, how constructs were measured or how they were conceptualised.

2.1.2 The Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) (figure 2.3) (Ajzen, 1988) was developed out of the Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975), which posits that behaviour is predicted by intentions, that in turn are predicted by attitudes, subjective norms and perceived importance of norms. Outcome expectations are incorporated into the model as beliefs towards an outcome, which then influence attitudes. Whilst the TRA has been tested in a wide variety of behaviours (Sheeran & Taylor, 1999; Moore et al., 1998b; Theodorakis et al., 1991), it was specified for use with behaviours under volitional control. However, this does not apply to all behaviours and so the TPB includes a control element and attempts to explain those behaviours not completely under volitional control, i.e. where potential barriers exist. When the two models were compared, the TPB accounted for significantly more variance in behaviours perceived to be under low control, but no difference was found for behaviours under high or medium control, or for behavioural intentions (Madden et al., 1992).

As with the HBM the TPB includes outcome expectations, operationalized as beliefs about the outcome, but has no role for risk expectations. Intentions have been shown repeatedly to be the biggest single predictor of behaviour (Dzewaltowski et al., 1990; Rutter, 2000), whilst perceived behavioural control and attitudes are frequently the most significant predictors of intentions (Ajzen, 1991).

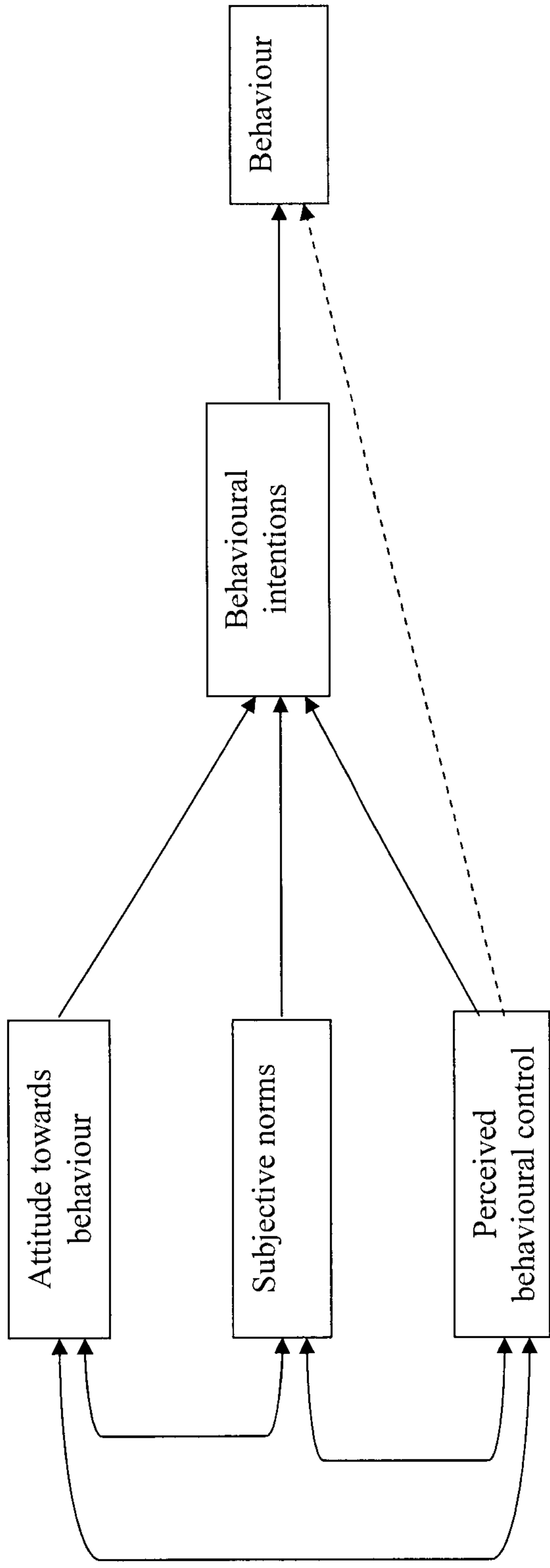


Figure 2.3 Theory of Planned Behaviour (Ajzen & Madden, 1986; Ajzen, 1988)

The TPB has been successful in predicting a variety of behaviours, including cycle helmet use (Quine et al., 2001), dietary behaviours (Povey et al., 2000), exercise (Courneya, 1995) and condom use (Bennett & Bozionelos, 2000). However, there is debate over how items should be scaled and scored, as this can produce vastly different scores and directly influence results (Sparks et al., 1991; Hewstone & Young, 1988). It has also been suggested that perceived behavioural control should be divided into two factors; perceived control and perceived difficulty (Trafimow et al., 2002). In a meta-analysis of studies using these two factors perceived difficulty was superior to perceived control for predicting both intentions and behaviours, even after controlling for attitudes, subjective norms and perceived control (Trafimow et al., 2002).

A meta-analysis of the TPB was conducted that included only prospective measures of behaviour (Armitage & Conner, 2001). The model was found to account for 27% and 39% of variance in behaviour and intentions respectively, and the attitude-intentions correlation was significant, explaining 24% of the variance in intention. A narrative review of interventions using the TPB found that the theory was used most often to measure process and outcome variables, predict intention or behaviour, and less often to develop the intervention. Effect sizes for changes in intention and behaviour were in the desired direction, but could only be calculated for 33% (changes in intentions) and 38% (changes in behaviour) of interventions. Limited information was provided so it was difficult to judge the effectiveness of the TPB (Hardeman et al., 2002).

2.1.3 The Protection Motivation Theory

The Protection Motivation Theory (PMT) (figure 2.4) (Rogers, 1975) was originally designed to explain fear communications and utilises the severity and vulnerability elements of the HBM, behavioural intentions from the TRA and self-efficacy from

Bandura's social learning theory (Bandura, 1977). Outcome and self-efficacy expectations are integrated into the model in coping appraisal, and risk expectations are operationalised as severity, vulnerability and fear in threat appraisal.

Studies examining PMT components have found significant roles for response efficacy (Stanley & Maddux, 1986), vulnerability (Wurtele & Maddux, 1988) and self-efficacy (Fruin et al., 1992; Wurtele & Maddux, 1988) on intention to exercise. With regard to actual behaviour, the PMT model explained 32% and 27% of variance in exercise behaviour and adopting a low-fat diet respectively in a group of cardiac patients (Plotnikoff & Higginbotham, 1998), whilst severity and self-efficacy explained a significant amount of variance in dental flossing behaviour (Beck & Lund, 1981). In a study of exercise behaviour PMT variables significantly predicted exercise intentions but not behaviour, but the addition of an implementation intention intervention saw a dramatic increase in subsequent exercise behaviour (Milne et al., 2002). In addition, PMT variables did not significantly predict breast self-examination once past behaviour was included (Milne & Orbell, 2000). A meta-analysis of health-related threats found that all components correlated with intention in the expected direction (Milne et al., 2000). Threat variables were associated with intention less often than coping variables in correlational studies, but were better at predicting intention in experimental studies. Overall, threat appraisal was generally a poorer predictor of intention and behaviour than coping appraisal.

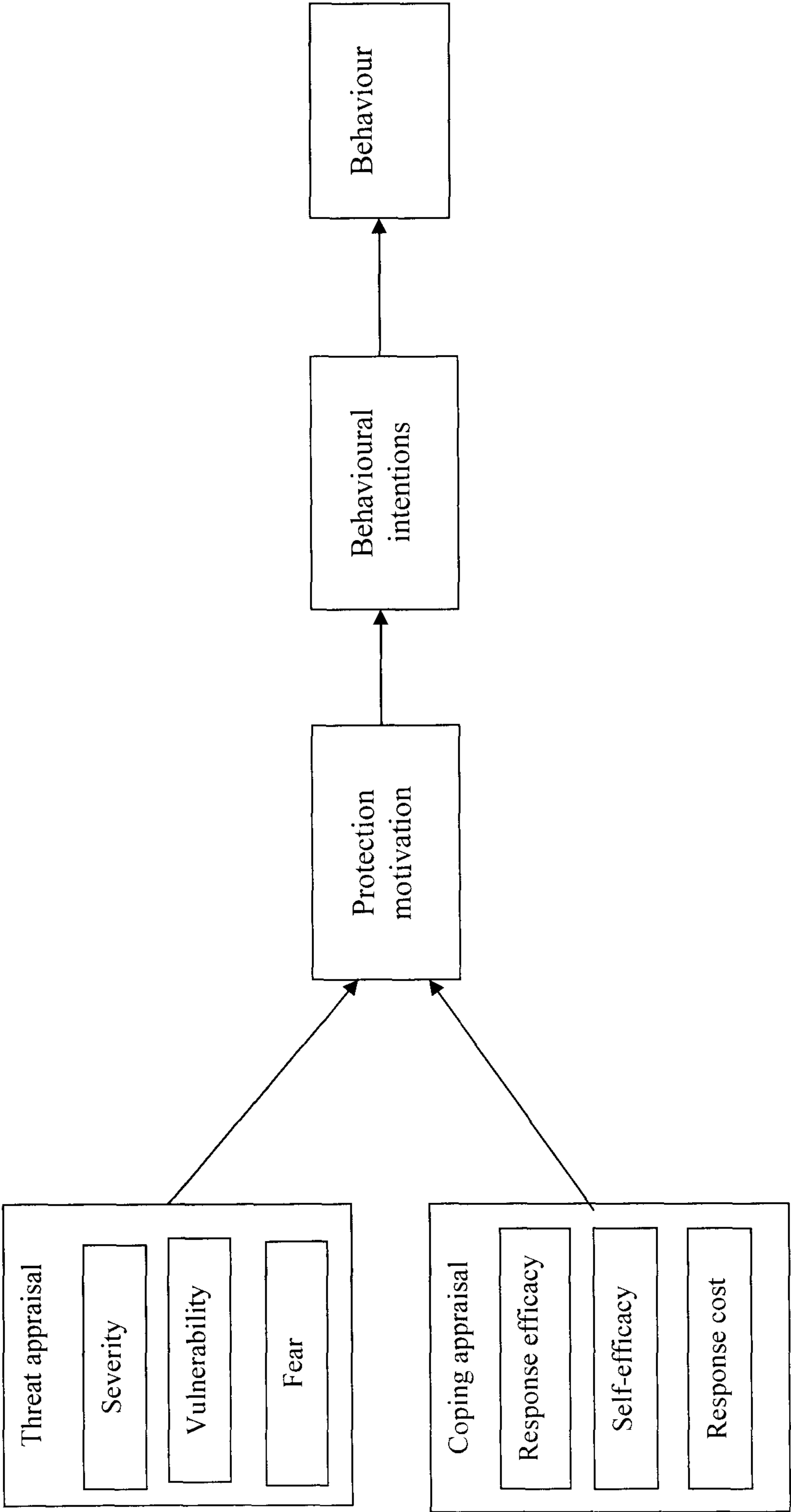


Figure 2.4 Protection Motivation Theory (Rogers, 1975)

Although all three types of expectations are incorporated into the PMT, there is a lack of explicit assumptions about cognitive processes when actions are initiated and maintained, and it provides little information on causal and temporal order (Schwarzer, 1992b).

2.1.4 The Health Action Process Approach

The Health Action Process Approach (HAPA) (figure 2.5), a synthesis of several models, is a self-regulatory model that explicitly incorporates risk, outcome and self-efficacy expectations (Schwarzer et al., 1992).

As with the PMT, the HAPA includes risk, outcome and self-efficacy expectations, but it is a process model with two stages: the motivational stage, containing the expectation components, and a volitional phase. In a study on healthy eating, 21% of variance in men's eating behaviour was predicted by intentions, self-efficacy and positive outcome expectancies, whilst 20% of variance in females was predicted by the same factors plus negative outcome expectancies (Schwarzer & Fuchs, 1996). Risk expectations were not significant for either intentions or behaviour, but only two questions examining risk expectancies were used compared to six items on self-efficacy and twelve devoted to outcome expectancies (seven positive and five negative outcomes). A study on testicular self-examination (TSE) provided partial support for HAPA; outcome expectations and self-efficacy were significant predictors of TSE in young men, as were knowledge and intentions (Barling & Lehmann, 1999).

The majority of the work using the HAPA has involved healthy participants, therefore risk expectations may not be as relevant as in participants with a chronic condition, but recent work has looked at motivational and volitional processes in patients undergoing

cardiac rehabilitation (Sniehotta et al., 2006). This extends work using the HAPA to look at action and coping planning, but retains risk awareness, and makes a useful distinction between (initial) action planning and more (long-term) maintenance coping planning (Schwarzer & Renner, 2000).

2.1.5 Leventhal's Self-Regulatory Model

The models described so far have largely focused on cognitive and related determinants of how individuals behave in order to maintain health. However, the way individuals react to a health threat is hugely important and this is the focus of Leventhal's Self-Regulatory Model (Leventhal et al., 1980). Illness representations form part of the Self-Regulatory Model of illness behaviour and are defined as implicit, common-sense beliefs held by an individual about an illness (Leventhal et al., 1980). Illness representations contain a number of attributes (consequences, identity, timeline, cure/controllability and cause) which determine the individual's reaction to a health threat (figure 2.6), with timeline, consequences and cure/controllability synonymous with expectations. The Self-Regulatory Model, and specifically illness representations, has made a significant contribution to the understanding of lay beliefs about illnesses and the effects these beliefs have on behaviour.

In a study on personal models, participants with OA believed it to be a fairly serious condition characterised by pain and stiffness, which is incurable but can be controlled through aspects of treatment (Hampson et al., 1994). In addition, the number of symptoms and the perceived seriousness influenced self-management strategies prospectively and concurrently. People with more symptoms and who perceived the condition to be more serious used a greater number of self-management strategies for both typical and worse days.

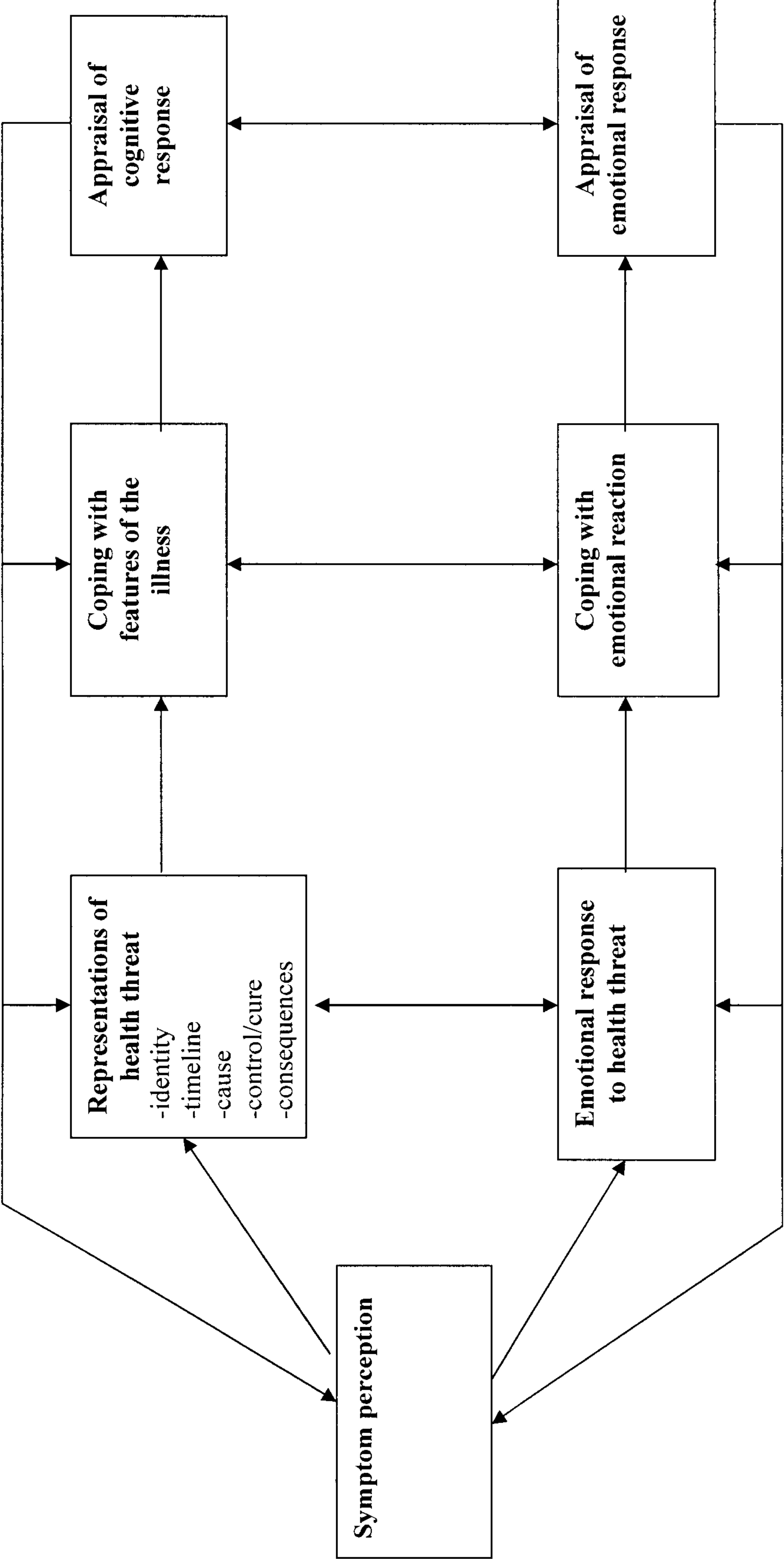


Figure 2.6 Self-Regulatory Model (Leventhal et al, 1980, 1984)

Semi-structured interviews were originally used to elicit illness representations but this method can be expensive and time-consuming. To measure illness beliefs quickly and in a standardised fashion the Illness Perceptions Questionnaire (IPQ) was developed, which utilises the five constructs identified in Leventhal et al's Self-Regulatory Model (Weinman et al., 1996). Support for the constructs and measure comes from a meta-analysis of 45 studies (Hagger & Orbell, 2003). High scores on illness identity, timeline and consequences components were associated with negative outcomes for psychological well-being and increased use of emotion-focused coping strategies, whilst high levels of cure/controllability were associated with better adaptive outcomes and disease state, and lower levels of psychological distress.

In oral surgery, pre-operative timeline expectations predicted return to work, expectations of control over recovery predicted healing and expectations of more severe symptoms predicted increased severity immediately following surgery, with expectations more important in predicting recovery than medical variables (McCarthy et al., 2003). Control and timeline expectations were not significant predictors of time taken to return to normal function, but were major contributors (over and above medical and anxiety variables) in predicting follow-up anxiety levels. In addition, the pre-operative illness representations were generally unrelated to pre-operative anxiety, indicating that anxiety and illness perceptions are separate factors. This is an interesting study, which illustrates the important role that illness representations can play. However, surgery is a discrete event with a definite "before" and "after", so it is necessary to examine illness perceptions in conditions where no discrete event occurs.

In a two-year study of women with RA, illness perceptions predicted more variance than disease activity for physical function, pain, depression and anxiety at three time points (except for physical function at two years). Specifically, stronger illness identity was related to worse baseline physical function, more severe consequences were associated with more pain, depression and worse physical function at the one-year assessment, and more pain, depression and anxiety at the two-year assessment. Higher scores for cure/controllability were related to less pain, depression, anxiety and better physical function at the baseline assessment and less depression and anxiety at the one-year assessment. However, illness perceptions did not predict adjustment longitudinally (Groarke et al., 2005).

Patient scores on subscales of the IPQ have been found to vary across chronic illnesses and to predict variations in a variety of conditions. In Irritable Bowel Syndrome (IBS) cure/controllability scores were found to predict quality of life, and serious consequences predicted anxiety scores, although some of the variance was mediated through coping strategies (Rutter & Rutter, 2002). Increased control perceptions and causal attribution of lifestyle were significant predictors of attendance at cardiac rehabilitation (Cooper et al., 1999), whilst lower consequences were associated with more positively perceived health, and high control beliefs and a stronger illness identity were associated with more clinic visits in individuals with psoriasis (Scharloo et al., 2000).

Illness representations incorporate several factors relating to a chronic condition and include a mixture of items that address both the present and the future, with timeline, consequences and cure/controllability relating specifically to

expectations. As demonstrated in this section, these have been shown to be important in predicting variance in a range of outcomes, highlighting the importance of expectations in chronic conditions.

2.1.6 Summary of Expectations Related to Health Behaviour Models

It becomes clear when reviewing health and illness models that the use of expectations, although not always explicitly termed so, are present in many different forms. This includes expectations about own behaviour, perceived vulnerability, the severity of an outcome, the timeline or consequence of a condition.

Although in previous research threat expectations have been shown to predict less variance than self-efficacy and outcome expectations, this may be due to how expectations were measured and the study populations used. Risk expectations are often measured simplistically with only a small number of risk items relating to the likelihood of developing a problem and the perceived severity of that problem. In addition the models are largely applied to healthy populations to investigate ways of changing behaviour, such as reducing calorie intake or increasing levels of exercise. These individuals may not feel their health is threatened, but in an existing health problem such as arthritis or diabetes, the risk may be far more salient. For these individuals, risk expectations may have a greater influence on behaviour when measured more comprehensively. Illness representations are currently the most useful way of eliciting people's ideas about the future course of their illness.

2.2 EXPECTATIONS: APPLIED APPROACHES

The previous section reviewed studies that used a theoretical framework. The following section reviews studies that have investigated expectations in an applied health setting, including those without a theoretical framework, and examines the issues associated with these studies. First, an outline of how expectations are defined is given.

2.2.1 Defining Expectations

A consistent definition of expectations is necessary to allow both accurate measurement of the concept and comparison across studies. However, expectations are not always explicitly defined, and when they are, some discordance exists. The majority of definitions start from a similar point, for example, that expectations are “beliefs about an event that will happen in the future” (de Groot et al., 1999). The event may be a physician consultation, a treatment regimen or the course of an illness. This definition views expectations as cognitions, that is, how we process and understand information in order to make sense of the world.

However, disagreement exists with regards to whether affective as well as cognitive components should be included. Buetow argues that the term expectations has two meanings; wants and predictions (Buetow, 1995), and Kravitz includes desires, wishes and entitlements in his definition (Kravitz, 2001).

However, others explicitly distinguish between expectations and desires (values), emphasising the cognitive nature of expectations (Uhlmann et al., 1984), or separate expectations from hopes, arguing that what a patient expects from a consultation, such as an injection, is not necessarily what they hope for or desire (Like & Zyzanski, 1987)!

Thompson & Sunol's review of expectations in relation to healthcare user satisfaction attempted to explicitly define expectations and produce a theoretical model (Thompson & Sunol, 1995), and identified four types of expectations:

- a) *Ideal* – what the consumer would most like to happen
- b) *Normative* – expectations based on what users think should happen, or what they believe is usual
- c) *Predicted* – what users think will actually happen in an encounter (this is closest to the most commonly used definition)
- d) *Unformed* – not strictly a type of expectation since it does not yet exist, this refers to users who are unable or unwilling to share their expectations (e.g. because they have no prior experience on which to base their expectations)

Work such as that described above, which seeks to clarify types of expectations, can instead create further confusion by labelling affective factors, such as ideal expectations, as cognitive, when they are effectively hopes (Janzen et al., 2006). Hopes and expectations are frequently used interchangeably (Mancuso et al., 1997; Meng et al., 2006), but studies would provide greater insight if expectations and hopes were measured separately, and the overlaps and interactions then examined.

The need to separate hopes from expectations is illustrated by a comparison of individuals' expectations and hopes, which found large differences between the two (Frowick et al., 1986). A questionnaire was administered to two groups of primary care patients; the first group rated the level of expected physician expertise for a range of problems, whilst the second group were asked to rate the level of expertise they would want from their doctor for exactly the same items, ranging

from no involvement through to expert help. The groups differed significantly on 40% of the items, and when levels of expected and desired involvement were compared there were several differences, highlighting the problems of using terms interchangeably.

2.2.2 Health-related Surgical and Non-surgical Expectations

Studies on health-related expectations have explored a number of areas, including types of expectations held and their effects, both for surgical and non-surgical conditions. Most studies on treatment expectations focus on surgical procedures as they provide a convenient opportunity to compare pre-surgical beliefs with post-operative outcomes and to examine whether expectations are significant predictors. Positive expectations have been linked to positive outcomes (including pain, function and depression) across a range of conditions, including Benign Prostatic Hyperplasia (BPH) (Flood et al., 1993) and OA (Mahomed et al., 2002; Orbell et al., 1998).

Surprisingly, expectations about the future course of a condition have received less attention. When 66 private RA patients were asked to complete measures of anxiety, functional health and future health expectations, significant correlations were found between functional health and future health expectations and those with poor self-rated functioning had negative expectations (i.e. they expected their health status to be limited in the next few years). However, no significant correlation was found between anxiety and expectations (Radanov et al., 1997).

Although their use of private patients may compromise the generalisability of findings, they are still interesting and suggest this area merits further investigation.

One of the major criticisms of studies, highlighted in section 2.1.4, is the lack of

work on risk expectations for a given condition and Radonov et al's study indicates that increased attention to these beliefs may provide valuable information on outcomes.

The expectations held by patients are generally overly positive compared to actual outcomes (Lindsay et al., 2000; McGregor & Hughes, 2002; Simpson et al., 1998), and these optimistic expectations may have important effects. Knee replacement patients with unfulfilled expectations were less positive about their general health and the future (Burton et al., 1979), and non-completers in an exercise prescription scheme showed a greater discrepancy between their current selves and what they expected or desired (Jones et al., 1998). Different treatments may also be linked with different expectations, which may subsequently influence treatment decisions (Marchant-Haycox et al., 1998).

A key assumption of research in this area is that patients hold definite expectations of treatment, however qualitative studies have suggested this is not the case, although following treatment participants were able to say how experiences compared to pre-treatment expectations (Haas, 1999; Woolhead et al., 2003). This relates to the concept of unformed expectations as outlined in 2.2.1, and participants may have held clear expectations at baseline, but not wanted to disclose them.

Several studies have examined expectations in musculoskeletal disorders, although it is a relatively under-researched area given the prevalence of these conditions. In surgical knee OA patients with higher expectations of surgery were less depressed nine months after their joint replacement (Orbell et al., 1998), whilst positive pre-

operative expectations for complete pain relief predicted better post-operative functional health and pain in hip and knee patients (Mahomed et al., 2002). In participants with chronic low back pain, positive expectations were also related to better outcome (Carosella et al., 1994; Alexandre et al., 2002; Harkapaa et al., 1996). Whilst these findings indicate the importance of positive expectations in musculoskeletal problems, qualitative work by Woolhead et al. (2003) highlights the difficulty with researching the role of expectations; several participants were unable or unwilling to talk about their expectations before surgery, but at the post-operative interview were able to judge whether the surgery had matched their expectations. To date, no published studies have looked at how higher expectations produce more positive outcomes. It is possible that expectations have moderating or mediating effects on outcomes, and may have a positive effect on motivation, or may increase an individual's level of commitment. Further work is required to explore these processes in musculoskeletal conditions.

2.2.3 Methodological Issues

Although a number of studies indicate that expectations may influence outcomes and the choices individuals make, there are methodological issues that should be addressed. A common problem is the use of a global item to represent expectations (Flood et al., 1993) which is unlikely to be sensitive enough to differentiate between different symptoms. This is a frequent problem in expectations research, and qualitative research has shown that people have expectations across several different areas which may be valued differently and have varying levels of perceived probability (Staniszewska, 1999; Haas, 1999).

The origins of expectation items used in questionnaires is often unclear, they may be derived from literature reviews, or developed on an ad hoc basis to include areas that researchers are interested in. This may affect the content validity, resulting in the omission of areas most relevant to patients. In a well executed study, a series of interviews were conducted with cardiac patients attending outpatient clinics, and the findings were then developed into a questionnaire (Staniszewska, 1999), which increases the likelihood of including valid items in questionnaires.

Studies also vary with regard to the type of expectations under investigation, for example expectations of treatment or the outcome of a condition. Due to the availability of patients and the relevance to clinical practice, the majority of studies focus on expectations of treatment. However, it is unclear how important these expectations are, or their relative weight compared to expectations of the condition itself, and patients do not view treatment in isolation but in relation to broader aspects of their lives. Little is also known about the interaction between treatment and outcome expectations, again because many studies only use a limited number of items to measure expectations, or about the interaction between generalised and specific expectancies (see Carver et al., 2005 for an exception).

Issues also arise with regard to how people rate their expectations and the extent to which users are able to distinguish between hopes and expectations; several studies reviewed in this chapter identified problems that participants had with expressing their expectations, comparable to the concept of unformed expectations (Thompson & Sunol, 1995). Interestingly, little information is available on participants who do not have or do not express (strong) expectations. For example, a large number of coronary artery bypass graft (CABG) patients did not, or could

not, express expectations, but it was not clear how these individuals differed from those with positive or negative expectations (Lindsay et al., 2000). Comparisons of those with strong expectations and those who are ambivalent may be an interesting area of investigation, as there may be differences in interpretations of health messages or receptiveness to interventions.

The main reason cited for conducting many expectations studies is patient education through identification of inappropriate expectations, but what is generally ignored is how these expectations develop. If, for example patients identify the media as a primary source of expectations, health education could be disseminated effectively in this way. Interviews with primary care patients who had unmet expectations following a consultation identified four sources of expectations; somatic symptoms, perceived vulnerability to illness, previous experience either related to self or to others, and transmitted knowledge (personal education, conversations with friends, relatives, physicians etc; and “instruments of popular culture” including magazine articles and television programmes). Only 7% of people identified transmitted knowledge as a source of expectations, suggesting that individuals form expectations from sources other than the media (Kravitz et al., 1996).

2.3 OPTIMISM AND PESSIMISM

Whilst specific expectancies have been widely used in behaviour models they have been unable to account for large amounts of variance in behaviour change. It is possible that generalised expectancies are important, and that the dispositional, relatively stable beliefs about future outcomes people hold may produce a different effect to situation-specific expectancies. Individuals with positive generalised

beliefs about the future are termed optimists, and those with negative beliefs pessimists. It is hypothesised that these generalised expectations have a significant effect on individuals' health outcomes, with optimists experiencing more favourable outcomes than pessimists. This may be due to optimists adopting more self-protective behaviours, such as adaptive coping (Scheier & Carver, 1987) and healthy eating (Scheier & Carver, 1992).

2.3.1 Measuring Optimism and Pessimism

The Life Orientation Test (LOT) (Scheier & Carver, 1985) is the most widely used measure of optimism and pessimism. It arose out of Carver and Scheier's control model of behavioural self-regulation (Carver & Scheier, 1982), which assumes that optimists would perceive outcomes as attainable and would continue to exert efforts at attaining these outcomes, even when doing so is difficult, whereas pessimists would be more likely to disengage from efforts to achieve goals. The LOT consists of 4 positively phrased, 4 negatively phrased and 4 filler items, rated on a 5 point Likert scale, from strongly agree to strongly disagree. Examples of the items include "if something can go wrong for me it will" and "overall I expect more good things to happen to me than bad". An important consideration in studies which use symptom reporting as the primary outcome variable is that individual differences may affect symptom reporting regardless of actual health state (Costa & McCrae, 1985).

2.3.2 The Effects of Optimism and Pessimism

In comparisons of optimists and pessimists, superior health has frequently been found for optimists. Healthy participants had lower diastolic blood pressure, even when anxiety was controlled for (Raikonen et al., 1999), Coronary Heart Disease

(CHD) patients had shorter recovery times (Scheier et al., 1989), higher ratings of progress from staff and better recovery than pessimists (Scheier et al., 1999); optimistic employees experiencing severe illness or death of family members took less sick days and returned to their pre-event level more quickly (Kivimaki et al., 2005).

In participants with knee OA, pessimists had significantly poorer scores on all four objectively measured tasks of functioning (walking, climbing stairs, getting in and out of a car and lifting an object) and once covariates had been controlled for pessimism was a stronger predictor of performance than both optimism (which only predicted walking distance) and depression (Brenes et al., 2002).

Optimists often use more task-oriented coping and less emotion-focused and avoidance coping than pessimists (Carver et al., 1989; Fontaine et al., 1993). Task-oriented coping increased in participants with Insulin Dependent Diabetes Mellitus (IDDM) over a twelve-month study period and predicted increases in outcome and efficacy expectancies as did a decrease in emotion-focused coping (Fournier et al., 2002). The authors suggest that patients who used more task-oriented and less emotion-focused coping over a six month period became more optimistic about their outcomes and abilities, which in turn influenced future coping strategies.

2.3.3 Methodological Issues

In the LOT optimism and pessimism are positioned at opposite ends of the same construct, with the implicit assumption that pessimism produces an equal and opposite effect to optimism. However, growing evidence exists that the two concepts are not “unidimensional bipolar”, but are in fact independent of each

other (Mroczek et al., 1993), so individuals can have high optimism scores without necessarily having low pessimism scores. Several studies report correlations between optimism and pessimism of approximately $-.50$ or lower, which, whilst being significant, are lower than expected for supposedly opposing dimensions (Dember et al., 1989; Myers & Steed, 1999; Marshall et al., 1992; Mroczek et al., 1993). However, some studies used narrow samples, which may have affected findings (Marshall et al., 1992; Mroczek et al., 1993).

Another concern regarding the LOT is the extent to which an overlap exists with other personality measures, particularly neuroticism. Neuroticism, or negative affect, is defined as a “broad, stable dimension of personality consisting of negative emotions including sadness, anxiety, guilt and anger as well as associated cognitive and behavioural characteristics, for example, low self-esteem, preoccupation and insecurity” (Smith et al., 1989, p.641). Whilst the LOT has been found to correlate most highly with another measure of optimism, the Generalised Expectations for Success Scale (GESS) (Fibell & Hale, 1978), significant correlations were also found between the LOT and two measures of anxiety (Taylor Manifest Anxiety Scale (TMAS) and the A-Trait anxiety scale) (Smith et al., 1989).

In a follow-up study using the same questionnaires plus a coping measure and a physical symptom checklist, similar findings were produced. When neuroticism was controlled for, the influence of LOT scores on symptom reports, coping, wishful thinking and avoidance became non-significant, as did the relationship between time 1 LOT scores and time 2 symptom reports when time 1 anxiety scores were controlled for (Smith et al., 1989).

Rather than the LOT being a measure of neuroticism, it is possible that pessimism is instead part of the set of variables that make up the broader construct of neuroticism (Scheier et al., 1994). This would explain the persistent, yet moderate correlation between the two, and also why neuroticism regularly explains more variance than optimism and pessimism. Studies should therefore include a wide range of measures that may overlap with neuroticism.

To answer criticisms of the LOT, particularly relating to overlap with other variables, a factor analysis was conducted using several variables that may overlap with optimism (depression, neuroticism, self-mastery, self-esteem, trait anxiety, physical symptoms and coping) in a sample of over two thousand students (Scheier et al., 1994). Moderate correlations between the LOT and self-mastery, trait anxiety (the lowest at $-.50$), neuroticism and self-esteem were found. Trait anxiety had higher correlations with neuroticism ($.74$) and self-esteem ($-.72$), suggesting that whilst there is a degree of overlap between optimism and constructs such as neuroticism and anxiety, they are not the same. Optimism was a unique predictor of planning, reinterpretation and growth, seeking instrumental social support and turning to religion.

The revised LOT (LOT-R) (Scheier et al., 1994) consists of three positively and three negatively phrased items, plus four filler items and although high internal consistency and test-retest reliability scores were produced, it is unclear whether it is a better measure of optimism and pessimism than the original. There is only one instance where they have looked at the same procedure, coronary artery bypass

surgery, but different outcomes were measured (Scheier et al., 1989; Scheier et al., 1999).

2.4 UNREALISTIC OPTIMISM

Whilst there are benefits for holding optimistic beliefs, an important question is whether it is possible to be *too* optimistic, and if so, what effects do these beliefs have on an individual's behaviour? The concept of unrealistic optimism, or optimistic bias, arose from work on risk perception, and is defined as a belief held by an individual that they are invulnerable; "they expect others to be the victims of misfortune, not themselves" (Weinstein, 1980, p.806). This bias is a more extreme form of optimism than a general positive outlook for the future, and may be problematic as unrealistically optimistic individuals may ignore health warnings, believing they are not at risk. Unrealistic optimism is measured by self-report, yet it is difficult to quantify in individuals who may have a valid reason for believing that a positive event is more likely to happen to them than to others. However an overall positive bias in a group population is unfeasible – not everyone can have more good than bad things happen to them.

The phenomenon of unrealistic optimism has been investigated primarily in relation to health and to road safety. In college students, 34 out of 45 health hazards (including asthma and cancer) showed optimistic bias, with only ulcers showing negative bias. In addition, unrealistic optimism increased with perceived controllability but decreased with personal experience of the risk (Weinstein, 1982). In exercise behaviour, college students with high optimism and high unrealistic optimism had the largest decrease in self-reported exercise over a six week period, whereas those with high optimistic bias and low unrealistic optimism

reported the most exercise behaviour (Davidson & Prkachin, 1997). The authors suggest that increased exercise behaviour is due to both a generally positive outlook and an awareness of potential health threats, and that separating unrealistic optimism from dispositional optimism is a valid approach.

Much of the work on optimistic bias has used samples of college students, limiting generalisability to the wider population. When health threats were examined in an adult population the most powerful factor was absence: if a health threat had not already been experienced, it was perceived as less likely to occur in the future (Weinstein, 1987). Findings were similar to those of studies with college students: optimistic bias also increased as perceived preventability increased and decreased with increased frequency (the perceived number of people who would be expected to experience the problem in the course of their lifetime) and personal experience, including family history, of a problem.

Unrealistic optimism was related to the HBM in screening for breast and prostate cancer to determine whether optimistic bias was found in all elements of the model, or just in risk (Clarke et al., 2000). For breast cancer, bias was found in all elements of the HBM apart from screening, whilst for prostate cancer it applied to all elements. These results indicate that this bias pervades several aspects of the way we view future events, rather than simply the risk element.

The majority of studies in this area have been cross-sectional, so cannot shed light on the extent to which unrealistically optimistic beliefs relate to actual future events. In a large, longitudinal study on optimistic bias in driving, motorcyclists displayed significant optimistic bias in relation to the likelihood of accidents

occurring in the following year both for comparative risk and absolute risk of death or injury (Rutter et al., 1998). A year later, participants were sent a questionnaire regarding spills or accidents since baseline. As with Weinstein's study (Weinstein, 1987), experience with an accident, either for themselves or friends and family, was associated with an increase in perceived risk. For actual behaviour, the greater the perceived risk at baseline, the more risky the behaviour at follow-up, including losing concentration, or riding too close to other vehicles. It is possible that respondents who reported risky behaviour were realistic about their chances of having an accident; 35% of those who had reported an accident at baseline reported one or more further accidents in the following year, whereas almost 80% of respondents reported no accidents at either time point.

Many of the studies that have examined optimistic bias have used hazards or events that vary in the probability of them occurring, for example being in bed ill for two or more days, or being sued. For many people these threats are generally hypothetical and therefore may not be taken seriously. A Polish study conducted several weeks after the Chernobyl nuclear disaster included potential hazards regularly included in studies on unrealistic optimism, along with developing cancer, an event closely related to radiation exposure (Dolinski et al., 1987). An optimistic bias was found for all the items apart from developing cancer at one and five years follow-up, suggesting that the nuclear accident had increased participants' perceived risks of developing cancer. Little work has been conducted on optimistic bias in chronic illness, so it is difficult to predict whether findings generalise to other health-related conditions, but in patients with Multiple Sclerosis (MS) an optimistic bias was found for negative, but not positive events, i.e. they

believed themselves to be less susceptible to negative events but not more likely to experience positive events (Fournier et al., 1999).

A potential problem with research in this area relates to how optimistic bias is defined. Weinstein's definition related optimism to a comparative risk with other individuals (Weinstein, 1980). Harris and Middleton, however, identified three types of optimism; optimism as defined in section 2.3; comparative optimism, analogous with Weinstein's definition, and unrealistic optimism, which they define as the perception that positive events are more likely, and negative events are less likely, to occur (Harris & Middleton, 1994). Whilst these differentiations between the definitions make intuitive sense, judging whether an individual displays unrealistic optimism is difficult, and people are generally more likely to compare themselves to other people. An illustration of the need to be clear about which version of unrealistic optimism is being used comes from the study by Clarke et al outlined above (Clarke et al., 2000). Whilst the perceived chance of developing breast or prostate cancer was low compared to other people, it was significantly higher than the *actual* risk, so using Harris and Middleton's definition of unrealistic optimism, optimistic bias did not occur in this sample but comparative optimism did.

Getting individuals to make comparative judgements can also be problematic. For example, with the lack of specificity more information may be required to make a judgement (McKenna, 1993) and perceptions of invulnerability may vary depending upon the comparison target. In an elegant study, evidence of perceived invulnerability was only found when participants compared themselves with an average student or a friend, not with their closest friend (Perloff & Fetzer, 1986).

In addition, people rating themselves against a friend appeared to select different friends who fulfilled perceptions of different risk factors. Researchers need to be specific about who they want participants to compare themselves to, and also take into account the possibility that risk perceptions will vary depending on who are used as targets.

Unrealistic optimism refers to a specific type of expectation where individuals not only assess the likelihood of an event occurring, but expect positive events to happen to them and negative events to happen to others. Unrealistic optimism appears to be a common occurrence and may serve as a protective function, reducing anxiety. It may also encourage reckless or dangerous behaviour if people feel that they are not at risk. Future research in this area should be more specific with regards to the comparison target, and expand the study population into those with chronic illnesses to explore how this bias influences their illness or health outcomes.

2.5 POSSIBLE SELVES

Possible selves form part of the self-concept and are ideas or beliefs specific to a person's image of their self, relating to how individuals envisage themselves in the future. They enable the self to be a dynamic construct existing in more than one time dimension, and because possible selves are imagined rather than actual, they may not necessarily be anchored in 'social reality' (Markus & Nurius, 1986).

Possible selves consist of three areas: (i) probable or expected selves (what people think will happen in the future), (ii) hoped-for selves and (iii) feared selves, with (ii) and (iii) related more to affect than probable selves (Markus & Nurius, 1986).

An important aspect of the possible selves concept is the acknowledgement that a hoped for self may not necessarily be reflected in an expected self. For example, an individual may hope to win the lottery, but not expect this to occur. This distinction is rarely made explicit in the majority of the literature on expectations, where hopes and expectations are often used interchangeably (see section 2.2.1). Probable selves are expectations about the future which can incorporate risk, outcome and self-efficacy expectations, but solely in relation to the self.

In the Possible Selves Questionnaire respondents are asked to decide the extent to which each item describes them at present, whether it has ever described them in the past, whether it is ever considered as a possible self, how probable the self is for them and how much they would like it to come true (Markus & Nurius, 1986). An adapted version has been used as an interview format with older adults in which possible selves are generated for hoped and feared selves (Hooker, 1992; Hooker & Kaus, 1994). The importance of each self occurring (or not, in the case of feared selves), the likelihood of this happening (outcome expectancy) and the amount of control they feel that they have over the outcome (perceived efficacy) is then rated.

The majority of studies looking at possible selves from a life-span perspective have been cross-sectional, comparing different groups. However, a longitudinal study of older adults found that over a four year period new selves continued to emerge, with 72% of participants adding new hoped-for selves and 53% adding feared selves (Smith & Freund, 2002). In addition, the dominant motivational orientation was not maintenance as hypothesised, but improvement. This finding highlights the importance of examining possible selves longitudinally.

Whilst the work on possible selves is interesting, particularly in its life-span perspective, problems exist (Markus & Nurius, 1986). The majority of work has focused on hoped-for and feared selves only (Cross & Markus, 1991; Hooker, 1992; Hooker & Kaus, 1994), and there may be an assumption that expected selves are too difficult to elicit from patients, or that hoped-for selves are analogous with expectations. However, a study on possible selves in optimists and pessimists suggest that both of these points are incorrect: participants were capable of producing all three types of possible selves, and whilst optimists and pessimists hoped good things would happen to them, only optimists expected it (Carver et al., 1994)! In addition, the original work using the possible selves questionnaire examined the relative importance of probable and hoped for selves (Markus & Nurius, 1986). Both areas made significant contributions to levels of esteem, negative affect and helplessness, but the highest addition to the variance not explained by the ‘now’ self came from probable selves.

An additional problem is that the majority of studies have been cross-sectional, and whilst possible selves have been examined longitudinally, these studies have had long intervals, for example four and five years (Smith & Freund, 2002; Frazier et al., 2000), producing snapshots at two time points rather than longitudinal studies with regular follow-up intervals.

2.6 THE PLACEBO EFFECT

Applied expectations have been present in the medical field for many years in the form of the placebo effect. This occurs when patients given an inert substance experience effects, either positive (placebo) and negative (nocebo), which are

synonymous with the active substance they believe they have received. In this way, the expectations of the effect of treatment manifest themselves in a perceived change in the condition.

Placebos are most commonly used in pharmaceutical trials, but have also been employed in non-pharmaceutical interventions such as exercise. In a small study testing expectancy manipulations, two groups experienced identical training regimes, with the exception that one group was repeatedly told about the psychological benefits of exercise (Desharnais et al., 1993). The only significant difference between the two groups was on self-reported ratings of self-esteem, suggesting that the experimental group's improvements were due largely to the expectancy manipulation. However, there were slight increases in self-esteem over time in the control group, indicating that other factors, including the exercise process may have been partly responsible for the changes.

Despite many studies reporting evidence of placebo effects, controversy still exists. No evidence for a placebo effect was found in a systematic review, except in a sub-analysis of 27 pain studies, where a significant placebo effect was found (Hrobjartsson & Gotzsche, 2001). Many conditions may show natural improvement or fluctuate over time, which would result in an overestimation of the placebo effect and differences in placebo responses may also occur between trial and clinical situations. If informed consent has been properly obtained participants will be aware that they have a chance of receiving a placebo so their expectations of improvement may not be as great as those receiving a placebo in a clinical setting where they may unequivocally expect improvement. In a research trial, this would result in an underestimation of the placebo effect.

It is often extremely difficult in placebo trials not to unblind participants, and so placebos are required that mimic the active substances as closely as possible, in terms of appearance and side effects. A related problem exists in crossover trials where participants may be able to identify the placebo substance once they have experienced both, and unblinding difficulties are even greater in non-pharmaceutical trials where participants *have* to take an active role.

The placebo effect is an interesting example of applied expectations, as the belief that an individual is receiving a treatment appears in some cases to influence perceptions of their condition. However, expectations are one of many different explanations for placebo effects, along with emotional change theory, classical conditioning and the biological approach (Stewart-Williams, 2004), and to gain a clearer picture of the magnitude of the effect methodological improvements are required (Hrobjartsson, 2002).

2.7 SATISFACTION

A great deal of work has examined expectations as determinants of patient satisfaction and a detailed literature review is beyond the scope of this thesis. However, the following section provides a brief overview.

The expectancy disconfirmation theory has been the overriding theory in work on patient satisfaction for many years, and states that satisfaction is a result of a comparison between expectations and outcome (Thompson & Sunol, 1995). An individual with negative expectations but a positive outcome would therefore be expected to experience more satisfaction than an individual with positive

expectations and a positive outcome. However, the findings using the expectancy-disconfirmation theory have been mixed (Thompson & Sunol, 1995) and several problems exist; the model is purely cognitive, and has no room for social aspects such as social comparison, or affective aspects such as anxiety. Moreover, it is linear (a straight forward relationship), and only focuses on outcomes of, for example, a consultation or an operation.

Whilst a number of theories were proposed to conceptualise the interaction that exists between expectations and experience (Ross et al., 1987), there has been an overall lack of theoretically based work. In addition, many studies do not explicitly define either expectations or satisfaction, which may result in a lack of generalisability across studies, as it is unclear what is actually being measured.

Five hypotheses were generated to examine the impact of expectations and values on satisfaction with care in primary care settings (Linder-Pelz, 1982). Some support was only found for the hypotheses that when the magnitude of baseline expectations were taken into account, people were more satisfied if occurrence exceeded expectations, and people who had positive expectations and experienced positive occurrences had higher levels of satisfaction compared to those with high expectations and unfavourable outcomes. This is an important study, which is theoretically underpinned. However, areas of satisfaction were sometimes measured using single items rather than scales and the number of antecedents did not match the satisfaction items, which, as the author acknowledges, may reduce the stability of the measures and bias the findings.

To date, the link between expectations and satisfaction has some, but not overwhelming, support. Future work should take into account the complex nature of satisfaction and its multiple determinants, which may vary in importance depending upon the situation under investigation.

2.8 SUMMARY

This chapter has examined in detail work on expectations, both theoretical and empirical, and specific and general (e.g. optimism and pessimism), and has given suggestions for future work. Expectations have been widely used in various forms to try and predict outcomes and behaviours in health and illness situations, and previous work suggests they may play an important role. However, studies have mainly focused on self-efficacy and outcome beliefs, whilst giving little attention to expectations about an illness or condition. Illness representations have come closest to this by looking at beliefs in terms of timeline, consequences and so on. In addition, the majority of research has examined specific expectations, usually for treatment, without considering the longer term expectations of an illness as a whole, or examining both specific and generalised expectations together to gain an understanding of their relative contributions.

CHAPTER 3: SYSTEMATIC REVIEW OF THE IMPACT OF EXPECTATIONS ON HEALTH-RELATED BEHAVIOUR

3.1 INTRODUCTION

Standard reviews of medical literature have been criticised for often being “subjective, scientifically unsound and insufficient”, and there has been a call for an increase in systematic reviews in which studies are critically explored, evaluated and synthesised (Mulrow, 1987). Systematic reviews should provide a clear, structured method for identifying and selecting information (Mulrow, 1987), and locating the information is considered to be as important as the appraisal. They differ from standard literature reviews as well-defined criteria are applied to the selected studies to assess their quality, and a weighting system can be used to account for more important criteria, such as sample size, study design and data analyses. In many areas it is possible to conduct a meta-analysis, which combines the results from studies addressing the same question. This allows conclusions to be drawn about that particular topic (Petitti, 1994).

Previous research has looked at various aspects of health-related expectations, including the types of expectations held and their outcomes (Mahomed et al., 2002), and relationship to behaviour (Brenes et al., 2002). Because expectations have been applied in diverse ways and in different conditions, a systematic approach can establish how effective and reliable previous findings are. In a systematic review on treatment expectations in back pain participants expressed a wide range of expectations related to many aspects of treatment, which often were not met (Verbeek et al., 2004). In a review of recovery expectations (including self-efficacy expectations) in a wide range of conditions, including alcoholism, cardiac surgery

and obesity, positive expectations generally resulted in positive health outcomes, although the strength of the relationship depended upon factors such as the clinical condition (Mondloch et al., 2001). Whilst expectations may be influential in health outcomes regardless of the condition, focusing on studies that investigate a narrow range of conditions would provide a clearer idea of the effect of expectations in that particular area.

Whilst cognitions are hypothesised to influence behaviour, no systematic reviews have looked at the influence of expectations solely on behaviour. In Mondloch et al.'s review some studies looked at beliefs and others at behaviour, whilst some behaviours were measured using self-report and others observed behaviour (Mondloch et al., 2001). Consequently it is unclear how important expectations are in relation to health behaviour, or what the major methodological issues are. In addition, interventions are increasingly used to try and modify behaviour in people with chronic conditions. These interventions are often time-consuming for participants and so a better understanding of how expectations influence behaviour may enable the development of more effective interventions to modify behaviour and potentially improve outcomes.

A systematic review of this research enables a detailed examination of the ways in which expectations have been studied, assimilates the findings, highlights ways in which studies can be improved upon, and can identify areas that have yet to be thoroughly investigated. Appraising the quality of studies is important if findings are to be applied to health care settings; results may be misleading if the study is methodologically poor.

This systematic review focuses on expectations of individuals with chronic joint pain in the back and lower limbs because of the widespread prevalence of pain at these sites (Dillon et al., 2004; Peat et al., 2001) and the reliance on self-management as an intervention (Von Korff et al., 1998). Measures of objective behaviour (i.e. observed behaviour) are examined rather than self-report behaviours which, whilst convenient, are open to potential recall bias and social desirability (Vitolins et al., 2000). A range of objective or directly observable measures are available to measure behaviour such as medication adherence or exercise adherence, which can avoid these issues (Vitolins et al., 2000). Longitudinal studies which incorporated interventions were chosen to enable an examination of the predictive power of expectations on behaviour.

The title of the review is “*The impact of expectations on health-related behaviour in people with chronic joint pain of the lower limbs and back*” and aims to look at how expectations relate to behaviour in chronic lower limb and back joint pain, and how satisfactory the psychological and methodological aspects of the appraised studies are.

3.2 METHODS

Where possible, QUOROM guidelines (Quality of Reporting of Meta-analyses, Moher et al., 1999) for reporting findings were followed.

3.2.1 Search Strategy

Singular and plural terms were included, as were English and American spellings, and searches were conducted with and without the MESH option. Databases were searched from their inception up until 29th February 2004. At this stage the review aimed to be as inclusive as possible. Table 3.1 shows the search strategy used.

<i>Expectation(s) or</i>	<i>Behaviour(s) or</i>	<i>Osteoarthritis or</i>
Expectancy/ies	Behavior(s)	Musculoskeletal disease(s)
Belief(s)	Action(s)	Musculoskeletal condition(s)
Misconception(s)	Activity/ies	Degenerative joint disease(s)
Idea(s)	Aerobic(s)	Low back pain
Assumption(s)	Isometric(s)	Osteoarthrosis
Presumption(s)	Exercise(s)	Rheumatism
Perception(s)	Physical activity/ies	Chronic joint pain
Outlook(s)	Exertion(s)	
Probability/ies	Medication taking	
Thought(s)	Physician visit(s)	
Optimism/optimistic	GP visit(s)	
Pessimism/pessimistic	General Practice visit(s)	
	Primary care	
	Primary care visit(s)	
	Adherence	
	Compliance	
	Concordance	

Table 3.1 The search strategy used to identify suitable papers

Table 3.2 outlines the inclusion and exclusion criteria used. Only English language publications were accepted due to financial and time constraints. Cross-sectional studies were excluded, as a major aim of the review was to examine expectations as a cause of behaviour change. Although a large amount of work exists on fear avoidance in back pain (see Vlaeyen & Linton, 2000 for a review), it was not included in the review because the blurred distinction between emotions and pain-related beliefs may result in the inclusion of beliefs other than expectations. Conditions affecting the back and lower limbs were all included as the effects of increased pain and reduced functioning are similar.

Inclusion Criteria	Exclusion Criteria
Expectations measured at baseline	Fear avoidance behaviour
Behaviour measured	Retrospective
Longitudinal	Non-English language papers
Chronic conditions of the lower limbs or back	
Participants aged 18 years and over	
Journal publications	

Table 3.2 Inclusion/exclusion criteria for appropriate studies

An information specialist at the Chartered Society of Physiotherapy (CSP) also conducted an independent search to ensure a thorough trawl of a range of databases. Table 3.3 shows the databases searched. Hand searching of the following journals, again from inception up until 29th February 2004, was also conducted: Health Expectations; Psychology and Health; Health Psychology; and British Journal of Health Psychology. Zetoc alerts were set up to identify papers that were relevant to the review, but published after the cut off date, until 30th November 2004.

Author	Information Specialist
Medline	SMART (Sports medicine and related topics)
Psychinfo	HMIC (Health Management Information Consortium)
Embase	Embase
Cinahl (Cumulative Index to Nursing and Allied Health)	Cinahl
Amed	Amed
Cochrane / DARE (Database of Abstracts of Reviews of Effects)	Cochrane / DARE
Pedro (Physiotherapy Evidence Database)	Sports Discus
IBSS (International Bibliography of the Social Sciences)	CSP library system
ASSIA (Applied Social Sciences Index and Abstracts)	
Web of Science	

Table 3.3 Databases searched

3.2.2 Study Selection Process

The list of titles was scanned by the first author, and those which were irrelevant were excluded. The initial strategy was to be inclusive, and exclude unsuitable studies at a later stage. The abstracts of the remaining papers were collated and for each one the authors, institutions and journal details were removed to reduce any potential bias towards renowned authors or high impact journals (Jadad et al., 1996; Chalmers et al., 1981).

Two health psychologists and two academic physiotherapists reviewed the abstracts independently to assess their potential relevance. Each abstract was then classified as accept, reject, or unsure. Abstracts were rejected if, for example, the participant group was inappropriate, or there was no measure of behaviour. The reviewers then met to discuss decisions regarding suitability of abstracts. If no decision could be reached, the abstract went through to the next stage, where the full paper was reviewed.

Because over half of the studies had no abstract or little information, the full papers were obtained and their abstracts checked by the author for suitability. Thus all four reviewers did not have to rate papers which were not relevant. Studies that appeared to be suitable were then read independently by all four reviewers. A data collection form was designed to systematically extract data from the full papers, using recommended criteria (Chalmers et al., 1981; Pincus et al., 2002; Oxman, 1995). The main areas covered in the form were:

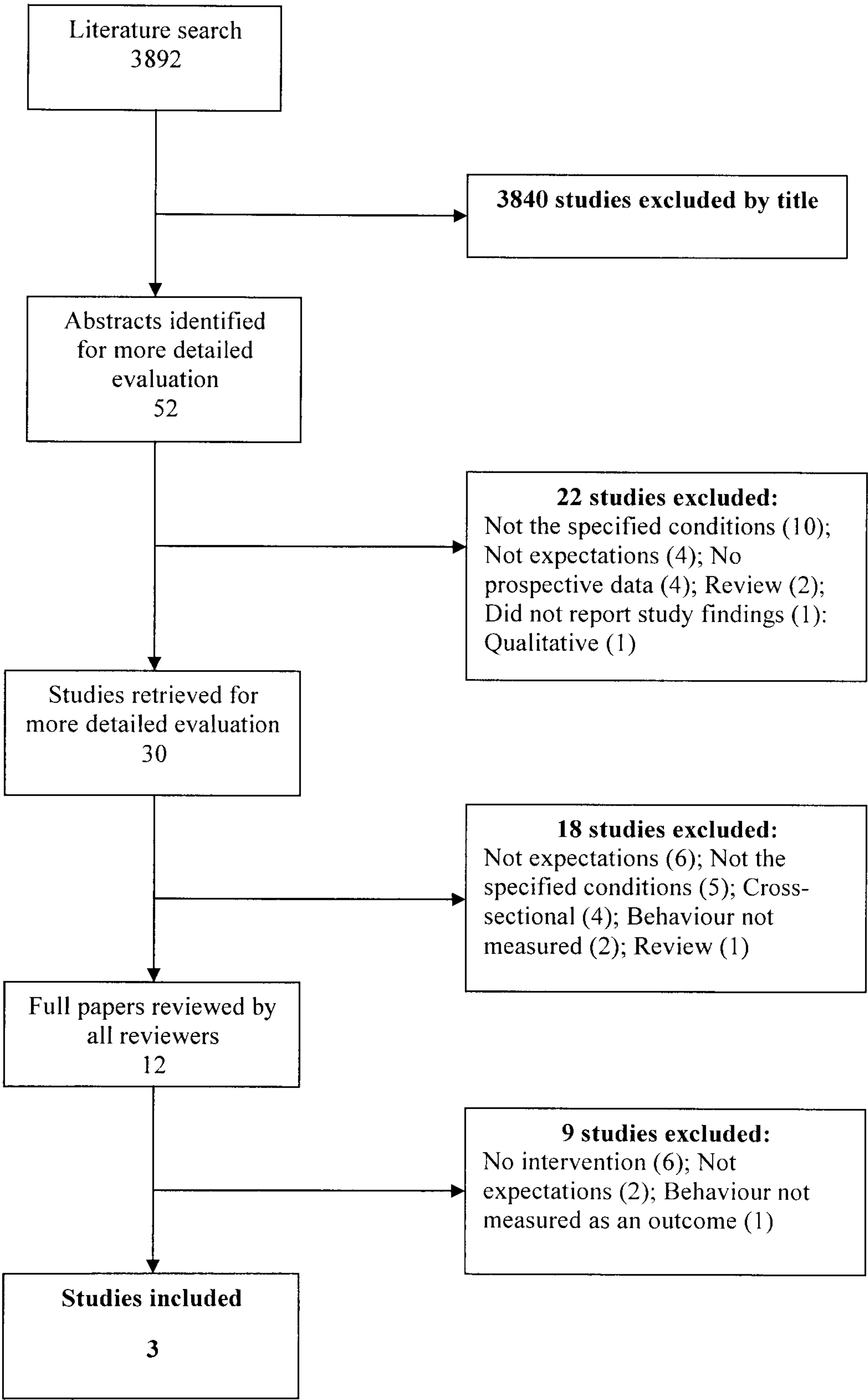
- Participants recruited (number, age range and mean, number female, ethnic groups, number of withdrawals)
- Clinical aspects (site of problems, symptoms durations, diagnostic method)
- Methodology (inclusion criteria, country study conducted in, power calculation, recruitment methods, selection procedure, randomisation methods & concealed allocation, study type)

- Expectations (what and how measured)
- Behaviour (what and how measured)
- Other variables measured
- Intervention (type, duration, methods of delivery, blinded assessments, follow-up period)
- Analysis (handling missing data, appropriate statistics)
- Results (main findings)

The form was piloted by all four reviewers on two papers to ensure important criteria were included. Copies of full papers were given to each reviewer to assess independently, and a separate form was used for each study. Following assessment of each paper the reviewers were asked to decide whether the paper should be rejected or accepted, and provide reasons for rejection. The reviewers then met to compare each paper and discuss their decisions and differences so that a consensus could be reached.

Twelve full papers were reviewed (figure 3.1). Nine papers were rejected for the following reasons: no intervention; expectations not measured; behaviour not measured as an outcome. This left just three papers that fulfilled the inclusion criteria. The authors of the accepted papers were contacted and invited to contribute any information they felt relevant. Further details on the intervention received by participants in the study by Carosella et al (Carosella et al., 1994) were provided by co-author Michael Feuerstein¹. Kristiina Härkäpää provided additional references relating to the Härkäpää et al study (Härkäpää et al., 1996), which did not relate to expectations, but described the intervention in more detail, covered the main treatment results and effects of health locus of control beliefs and psychological distress (Härkäpää et al., 1989; Härkäpää et al., 1991; Härkäpää, 1992). No response was received from Costa Alexandre or co-authors.

Figure 3.1 QUOROM flowchart for selection of papers (Moher et al, 1999)



3.3 ANALYSIS

The type of analysis used in systematic reviews depends upon the amount of homogeneity across studies. Due to differences in the way in which expectations and other variables were measured there was considerable heterogeneity, so a meta analysis was not possible. Instead, a narrative synthesis was used, where the differences between the studies, and how they relate to effectiveness, were examined (Bridle, 2003).

3.4 RESULTS

Table 3.4 summarises the key aspects of the studies. In all three, expectations had a significant effect upon participants' behaviour, with more positive beliefs related to better return to work status or higher adherence, although in Härkäpää et al's study the results were no longer significant when the covariate of baseline functional scores were included ($p = .63$).

Although detailed information on the interventions was limited, the programmes for the studies by Carosella et al and Härkäpää et al, which both focused on return to work, were similar; they comprised of strengthening and conditioning work, relaxation and stress management, and one-to-one consultations. Information was provided on non-completers (or those with low adherence) in the Costa Alexandre et al and Carosella et al studies; those with high adherence were more likely to be married or male (Alexandre et al., 2002) whilst completers were older, or work-disabled for a shorter duration (Carosella et al., 1994).

The type of expectations investigated and the way in which they were elicited varied; Carosella et al and Costa Alexandre et al focused on specific expectancies (return to

work and barriers to programme completion respectively), whilst Härkäpää et al looked at more general expectations regarding health. There was no information on piloting for the item used by Costa Alexandre et al, whilst the item used by Carosella et al had been used previously (Sandstrom & Esbjornsson, 1986), but no further information was given. Information on internal consistency was provided for the measure used by Härkäpää et al.

There was some overlap in terms of other outcomes measured, such as pain, depression and locus of control, although different measures were used. Härkäpää et al used measures that consisted of items from several well-validated measures such as the Beck Depression Inventory and the Health Locus of Control scale. Costa Alexandre et al and Carosella et al used a mixture of widely used outcome measures and visual analogue scales. The behaviours measured related to attendance at the intervention, i.e. programme completion or compliance levels (Carosella et al., 1994; Alexandre et al., 2002), or changes in return to work status (Harkapaa et al., 1996).

All three studies provided sufficient information on the analyses used and descriptive data on their samples. The analyses were appropriate, although in Härkäpää's study a logistic regression on predictors of return to work status, in addition to the one performed on functional capacity changes, would have been informative. None of the studies provided details on the amount, or handling, of missing data and little or no information was provided on ethnic groups, so it is unclear how representative the samples were of the general population. None of the studies clearly stated how participants were recruited, although Costa Alexandre et al did provide information on their procedure for obtaining informed consent.

Table 3.5 illustrates the methodological quality of the studies according to the pre-determined criteria. Although none of the studies met all of the quality criteria, they were drawn up with the assumption that randomised controlled trials (RCTs) would be included in the review, and so several were redundant, e.g. none of the studies used randomization methods or blinded assessments. Overall, the study by Costa Alexandre et al was the strongest methodologically.

The key finding from this synthesis is that more positive expectations were associated with more positive outcomes, but caution should be exercised due to the methodological issues raised.

Table 3.4 Table of reviewed papers

<i>Criteria</i>	Carosella et al (1994)	Costa Alexandre et al (2002)	Härkäpää et al (1996)
Country of study	U.S.A.	U.S.A.	Finland
Participants	-Low back pain -N=168 -Females=63 (38%) -Mean age=37	-Low back pain -N=123 (at baseline) -N=120 (98%) at completion -Females=76/120 (63%) -Median age=46.5	-Low back pain -N=237 at baseline -N=175 (84%) at completion -Females=84 (48%) -Mean age=42
Methodology	Quasi-RCT	Observational	Observational
Recruitment methods, diagnostic method	-Convenience sample (84 early discharge participants) & random selection (84 completers) -Medical record review and examination	-Convenience sample -Physician referral -Clinical evaluation by physiotherapist	-Consecutive participants -Physician referral
Expectations measured & method	-Return to work (RTW) expectations -0-10 VAS on the likelihood of returning to the workforce	-Expected barriers to regimen -Participants asked to identify one possible barrier at baseline -Attendance (i.e. compliance) at supervised exercise	-Health optimism -Health optimism scale based on Life Orientation Test (LOT) (5 items) -Changes in work status
Behaviours measured & method	-Completion of rehabilitation programme	-Attendance recorded	-Work status recorded at baseline and 12 months
Additional outcomes	-Information from patient records -Perceptions of disability -Pain VAS for severity & fear of re-injury -Perceptions of work environment -Personality style & psychological disorders	-External barrier of living alone -Pain intensity -Depression -Quality of life -Health Locus of Control	-Functional capacity -Locus of control -Index of depression -Work status changes
Intervention details	-Multidisciplinary work rehab programme -4 weeks duration, 3-4 hours a day, 5 days a week -Supervised exercise and counselling	-Supervised exercise, home exercise & education -6-12 sessions (varied between participants) -Supervision from physio, individually	-Multidisciplinary rehab programme -9 weeks duration (5 weeks home training, 4 weeks as inpatient), 7-8 hours a day -Supervised exercise & counselling

	-Secondary care setting	tailored plan	-Rehab foundation setting
Results – role of expectations	-RTW expectations accounted for 9% ($F=13.87, p < .01$) of variance in programme completion -Lower RTW expectations seen in non-completers	-Secondary care setting -Expected barriers predicted lower treatment adherence (OR:8.3, CI 2.6-26.8, $p < .01$)	-Participants who returned to work at 12 months had higher baseline levels of optimism than those still on sick leave (.008, $p < .05$)
Results – role of other variables	-Overall differences accounted for 34% variance in RTW status, $F(134,5) = 6.45, p < .001$ -Early dischargers perceived selves as more disabled, $t(145) = 1.98, p < .05$	-Those with co-morbidities had lower levels of adherence (OR:0.3, CI 0.1-0.9, $p < .05$) as did those with longer treatment duration (OR:0.3, CI 0.0-0.9, $p < .05$)	Baseline locus of control variables were not significantly related to return to work status at 12 months
Comments	-Limited information on recruitment -Limited measurement of expectations – 1 item only -Not clear what type of expectations RTW covers -Possible ceiling effect of work status -Intensive intervention	-Limited information on expectations – 1 item only -Clinically practicable intervention	-No information on the 26% who were non-completers -Possible ceiling effect of work status

Table 3.4 Continued

Table 3.5 Methodological quality of reviewed papers

	Methodological details	Carosella et al (1994)	Costa Alexandre et al (2002)	Härkäpä ä et al (1996)
1	Inclusion/exclusion criteria specified	-	+	-
2	Power analysis included	-	-	-
3	Recruitment methods reported	-	+	+
4	Randomization method performed	-	-	-
5	For expectations measures, reliability & validity checks conducted & measure piloted	-	-	Partial
6	Aims & objectives stated	+	+	+
7	Hypotheses stated	-	+	-
8	Blinded assessments	-	-	-
9	Assessments conducted by someone other than study team	*	+	*
10	Sufficient description of methods to allow replication	-	-	-
11	Withdrawals compared to completers (or low adherence compared to high adherence) on baseline variables	+	+	-
12	Handling of missing data reported	-	-	-
13	Descriptive statistics provided	+	+	+
14	Appropriate statistical analyses	+	+	+

+ yes, - no, * unclear/don't know

3.5 DISCUSSION

Following a narrative synthesis, expectations were found to be significantly related to behaviour. Participants with more positive baseline expectations were more adherent to the intervention or more likely to return to work. Even though the studies examined different behaviours and measured expectations differently, significant relationships were still seen between expectations and behaviour.

The reviewed studies had several strengths, including their use of objective measures of behaviour. Whilst self-report measures are fast, inexpensive and relatively easy to

collect they are open to bias if participants do not report information accurately. That positive findings were obtained with objective measures suggests that expectations did have a significant influence. Other strengths include a clinically practicable intervention (Alexandre et al., 2002) and the inclusion of a range of psychosocial variables, which provides more information on the influence of factors such as perceived disability on behaviour.

The review's findings must be considered in relation to limitations of the studies, for example, the types of expectations, how they were measured, and other methodological issues. All three studies used a limited number of items used to measure expectations, which were designed to answer specific questions and the issues associated with using a small number of items are discussed in the literature review (section 2.2.3). Also highlighted in the literature review is the ad hoc nature of the measures (section 2.2.3), which may have implications for the reliability and validity of the findings. This was seen in the Costa Alexandre et al study where no reliability and validity testing was reported.

Different types of expectations exist, and in the studies reviewed it is not clear which expectations were examined. Carosella's item on RTW expectations may reflect self-efficacy expectations (e.g. "I believe I am capable of returning to work"), outcome expectations (e.g. "I believe that after this rehab programme I will be able to return to work") or condition expectations (e.g. "I believe my pain and function will improve, allowing me to return to work"). The five item scale used in Härkäpää et al's study is based on the LOT (Scheier & Carver, 1985), and items can be interpreted as measuring different types of expectations, for example "I am sure I will never get

better” – condition expectations and “I am not getting rid of the pain, whatever I try” – self-efficacy or outcome expectations. Because the scores for each response are combined to provide a total score, it is difficult to determine which expectations are most influential.

In addition to issues around expectations, other methodological issues were highlighted, which may introduce bias and reduce the reliability of the findings. No information was given on the handling of missing data, a common criticism of studies (Roth, 1994). More information on missing data may highlight specific problems with the measures used, such as poor comprehension, and if a substantial amount is missing, there will be a loss of statistical power and a bias in parameter estimates (Roth, 1994); the findings may not be accurate, and it is not clear how generalisable the results are.

A potential source of bias in exercise-based interventions is that the participant cannot be blinded to their treatment arm. However, in the barriers study (Alexandre et al., 2002) the assessor was independent of the study and had no information regarding the participants’ attendance or adherence, so the possibility of biased assessments was reduced.

Despite looking at the relationship between expectations and behaviour, none of the studies took a process perspective. The mediational role of expectations on behaviour was not examined so it is not clear *how* expectations influenced behaviour. It would have been possible to examine the effects of the interventions on expected barriers and health optimism, but this was not done and represents a lost opportunity.

There are several limitations of this review that may have implications for interpreting the findings. Because of the heterogeneity of measures the data could not be pooled or an effect size calculated (Bridle, 2003), which would have provided a more definitive indicator of the influence of expectations. However, a detailed narrative synthesis, which enabled an in-depth, qualitative analysis, was possible, and highlighting the differences between the studies can identify potential sources of heterogeneity (Bridle, 2003).

Because a focused research question was employed, only a small number of studies focusing on low back pain were appropriate, making it difficult to generalise to a wider population. More studies may have included RCTs, enabling a more rigorous comparison between different groups, and studies where expectations had different or non-significant effects. A narrow research question was used to examine the role of expectations in interventions in related conditions, as these beliefs might be very different for acute, or potentially life threatening conditions. Expectations may also have different effects depending on whether the outcomes are behaviours or beliefs. This narrow focus is likely to decrease the generalisability, but will provide a clearer picture of how expectations affect behaviour in this case.

It is not clear why so few studies have examined expectations in relation to an intervention, although other psychological variables, such as self-efficacy or depression, may be considered more relevant or important. The range of behaviours covered in the review was very narrow, and so there are many health-related behaviours for which the influence of expectations is not clear, such as taking

medication or attending GP consultations. Further work is needed to ascertain the influence of expectations on other behaviours.

In a previous systematic review positive expectations were also related to positive outcomes across a range of conditions (Mondloch et al., 2001). The current systematic review extends knowledge about the influence of health-related expectations by focusing on a narrow range of conditions to provide a more precise picture of expectations, and by examining the types of expectations measured. The current review also gives a better idea of the effect of expectations specifically on behaviour. There has been little research examining the relationship between expectations and behaviour, which may be due to the issues associated with measuring behaviour and the reliance upon self-report measures. Further studies would provide a more rounded picture of how expectations influence behaviour.

This review, taken together with that by Mondloch et al (Mondloch et al., 2001), suggests that expectations have a significant effect on various health-related outcomes across a range of conditions, and that positive expectations generally result in more positive outcomes. Therefore, research into how to modify negative beliefs, and the exact effects of this modification should be the next steps in developing this work.

The review process revealed an emphasis on studies of low back pain as it is an incredibly common, and potentially disabling condition, but hip and knee joint pain is also prevalent and increasingly recognised as a major problem (Underwood, 2004). This emphasis on back pain may be related to the use of interventions based around

return to work; chronic hip or knee pain generally affects older individuals, so return to work may be an inappropriate outcome, but interventions of functional rehabilitation would be relevant. Hip and knee pain affects large numbers of individuals, and knowing the impact of expectations on outcome in those conditions could inform the development of self-management interventions.

To gain a clearer picture of the influence of expectations, it is necessary to resolve issues around the measurement of expectations. Well-validated and psychometrically tested measures are required, researchers need to distinguish between the types of expectations being examined (self-efficacy, outcome etc), and detailed information on the different types of expectations may indicate whether these different expectations vary in their influences upon behaviour.

Despite the very small number of studies reviewed, this systematic review indicates that positive expectations are related to positive outcomes in chronic joint pain in the lower back, and reflects the findings of other systematic reviews of expectations. However, more studies are required, particularly in chronic joint conditions other than the back, which employ more rigorous designs. It is important that the different types of expectations are taken into consideration, and measured and analysed separately to provide greater insight into the different influences they have on behaviour.

¹The programme consisted of stretching, then exercise prescription with aerobic exercise for cardiovascular conditioning (treadmill, upper body ergometer and exercise bikes) and a prescribed tailored muscle strengthening/conditioning programme. Both of these were individualised and monitored daily. The final element of the programme consisted of a pain and stress management group, focusing on work conditioning where participants went through the physical and psychological demands of their previous or future job.

CHAPTER 4: CROSS-SECTIONAL INTERVIEWS

4.1 INTRODUCTION

Chapter 2 described in detail the role of expectations in relation to health. These beliefs have been incorporated into theoretical models of health in various forms, including as expectations of severity and vulnerability in the Protection Motivation Theory (Rogers, 1975), and as outcome, self-efficacy and risk expectations in the Health Action Process Approach (Schwarzer et al., 1992). The influence of expectations has also been investigated in applied settings, for example in relation to the general outcome of a condition and as determinants of patient satisfaction, pain and function (Radanov et al., 1997; Iversen et al., 1998; Jackson et al., 2001).

There have been mixed findings with regard to the role of expectations in individuals' perceptions of their condition, and the extent to which they predict satisfaction, which may be due, in part, to methodological issues. The majority of work on expectations has been quantitative, with most measures developed without patient input, and consisting of only a small number of items, or a single global rating. Therefore the areas measured may not be relevant to patients, or may not be sensitive enough, as the limited number of items may not cover all areas that the patient has expectations for. For example, if participants are asked to rate their expectations of success for medication prescribed for their arthritis, their expectations for pain relief may be high, yet only moderate for functional improvement. A global rating scale would not detect these differences.

Qualitative methodology can be used to address these problems, as it enables in-depth exploration of a topic with a small number of participants. Previous qualitative work uncovered high expectations for coronary artery bypass graft (CABG) surgery for both specific aspects of the condition and wider areas such as independence (Lindsay et al., 2000), and in cardiac patients four main groups of expectations concerning their health and treatment were identified; expectations of the doctor, the nurse, the outcomes of care, and the patient's expectations of their own participation in care (Staniszewska, 1999). The expectations from these studies are unlikely to have been identified by researchers and clinicians, and would not have been detected in a questionnaire that used a small number of items.

Many studies also focus on patients' treatment expectations, which generally relate to a specific area and to a limited time period. In a systematic review of qualitative studies in chronic musculoskeletal pain, patients and GPs held similar expectations of the consultation namely; an equal relationship, to be taken seriously, straightforward communication (Parsons et al., 2007). Patients with a chronic condition such as OA receive no regular ongoing care and so may not hold these expectations, but may have ideas about what will happen with their condition in the future and the type of treatment they may receive at a later date.

OA is a chronic condition with no clear treatment path and with variability in terms of pain and function, so expectations may vary between individuals. Qualitative methodology can explore how participants form expectations, the types of expectations they hold and how these beliefs impact on other aspects of the condition. In addition, findings from interviews can be used to generate items for quantitative

measures, which may be more relevant to patients than those devised by researchers and clinicians.

This study uses a cross-sectional, semi-structured qualitative methodology to explore expectations held by this patient group and to generate items for the expectations measure, the development of which is described in chapter 6.

4.2 METHODOLOGY

4.2.1 Participants

Participants were recruited from four GP practices and a rheumatology outpatient department in South London. Participants were mainly recruited from primary care as the majority of people with OA are managed in this setting. However, participants were not excluded if they had previously been referred to secondary care, as long as they had neither undergone TKR nor were on a waiting list. Individuals with OA were also recruited from secondary care as their beliefs and experiences were of interest, as was the extent to which the two groups held similar expectations and had similar experiences of the condition. In addition, it was anticipated that recruiting from both primary and secondary care would provide a greater range of patient experiences than recruiting from primary or secondary care alone. Ethical approval to approach patients and conduct interviews was obtained from the King's Healthcare Research Ethics Committee (see appendix 1). Figure 4.1 lists the inclusion and exclusion criteria.

Figure 4.1 Inclusion/exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Male or female • English speaking • Fifty years old and over • Diagnosis of knee OA 	<ul style="list-style-type: none"> • Serious co-morbidities or terminal illness • Awaiting knee replacement surgery • Serious mental health problems e.g. psychosis

Because this study aimed to move away from examining expectations of a specific event or treatment, patients awaiting knee replacement surgery were excluded as they may have focused on the forthcoming operation rather than expectations of the condition in general. GP databases were searched under OA, knee pain and related terms, whilst hospital outpatient clinic letters were searched for patients with a primary diagnosis of knee OA. All participants had been diagnosed with symptomatic OA, but information on the proportion of those with radiographic OA was not available. Eighty nine suitable patients were identified (sixty nine from primary care), and sent a patient information pack which consisted of a cover letter from either their GP or Consultant, an information sheet, a reply slip and a pre-paid envelope. Those interested in participating were invited to either return the reply slip or contact the researcher by telephone.

Twenty nine patients originally agreed to participate, twenty two of whom were from primary care. Three were excluded from the final sample; one was interviewed but referred to her back OA more than her knee OA during the interviews, one was unable to participate before the end of the study (both primary care patients), and one from secondary care had problems understanding the interview questions. Table 4.1 shows participant and non-participant characteristics.

Table 4.1 Demographic data of participants and non-participants

	Primary Care	Secondary Care	All
Contacted	69	20	89
Mean age (range)	69 (52-92)	65 (51-80)	68 (51-92)
Female (%)	48 (70)	16 (80)	64 (72)
Participants (%)	20 (29)	6 (30)	26 (29)
Mean age participants (range)	72 (52-88)	64 (51-74)	70 (51-88)
Mean age non- participants (range)	68 (52-92)	65 (51-80)	68 (51-92)
Female participants (%)	13 (65)	5 (83)	18 (69)
Female non-participants (%)	35 (71)	11 (79)	46 (73)

Participants had a mean age of 70, and 18 (69%) were female. There was a similar uptake rate for patients in primary and secondary care, although more women took part from the outpatients group, which may reflect the fact that a higher percentage of women were contacted in this group. There were no significant differences in age between non-participants and participants ($p>.05$), or between primary and secondary care participants ($p>.05$). Of the study participants, twenty were Caucasian (77%) and 6 (23%) were Afro-Caribbean. Information regarding the ethnic background of non-participants was not available.

4.2.2 Procedure

Semi-structured interviews were used to allow exploration of themes that arose during the course of the interview. An interview schedule was developed (see appendix 2) consisting of broad issue questions covering all the areas of interest, and topical questions which acted as prompts to the interviewer. Broad areas such as current problems, onset and diagnosis, and management of the condition were included in the

schedule in order to gain an understanding of what living with arthritis involves. To explore expectations, issue questions concerned what patients thought would happen in the future with regard to their arthritis, what they initially thought would happen when their knee problems first started and why they held these beliefs.

Seventeen primary care patients were interviewed at their GP practice and three were interviewed in the medical school, which was close to their surgery but had more available space. Of the secondary care participants, four were interviewed in the Rheumatology department, one at home and one at their place of work. In all of the interviews only the participant and interviewer were present. Signed, informed consent was obtained before interviews commenced and, on average, they lasted 21 minutes (ranging from 9 to 41 minutes). Interviews were audio-taped and then transcribed verbatim by the author.

4.3 ANALYSIS

Analysis of the transcripts was based on Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA is a combination of phenomenological and symbolic interactionistic approaches and proposes that the meanings an individual ascribes to an event should be of central concern (phenomenology) but these meanings are only obtained through a process of interpretation, and meanings occur in, and as a result of, social interactions (symbolic interactionism). This view does not attempt to produce an objective account but rather looks at the lived experiences of individuals, in this case those with OA of the knee (Smith, 1996). According to this method, the interviewer is not a blank slate, but brings their own beliefs and ideas to the interview.

IPA has been used to explore a variety of health-related conditions including pregnancy (Smith, 1999), eating disorders (Smith et al., 1999), chronic benign low back pain (Osborn & Smith, 2006), and end stage renal disease (Smith et al., 1997).

The following analysis was based on normative IPA (Smith et al., 1999), which looks for broad, shared themes across transcripts. Transcripts were read repeatedly to ensure familiarity with their contents, themes of interest were identified and the transcripts were then coded (see appendix 2). This was an iterative process and some revision was necessary as new codes emerged. Once this had been completed the codes were collated and similar codes grouped into major themes, for example sections relating to pain, stiffness and mobility were grouped together under the theme of “characteristics of the condition” (see appendix 2).

The data for primary and secondary care patients were kept separate to enable a comparison of expectations between the two groups at a later stage. To ensure that themes had been categorised accurately, a second researcher read a sample of the interviews (seven primary and two secondary care transcripts) and coded them. Any discrepancies were discussed between the two researchers and changes to the coding scheme were made accordingly.

This study will focus on themes related to patient expectations, but an in-depth analysis of longitudinal interviews can be found in chapter 5.

4.4 FINDINGS

Very few differences were found between the primary and secondary care groups so the findings are described collectively, with differences highlighted where they arise.

4.4.1 Expectations about the Course of the Condition

Participants were asked what they thought would happen with regard to their knee pain in the future, in order to explore general expectations of their condition. Their responses could be grouped into ideas about the general outcome of their condition and specifically in relation to their treatment (global and specific expectations, Llewellyn et al., 2004). Outcome expectations centred round the extent to which the knees would deteriorate; participants expressed expectations in terms of the increase in severity of the condition, and how their functioning would be affected (numbers in square brackets refer to participants' code numbers, see appendix 2 for transcript notations):

It's not too bad at the moment but it's like everything else you just get older it gets more worn [11]

It's at the back of the mind now that they're not gonna give up completely so that I can't walk [13]

The use of these criteria produced comments that ranged from positive to negative, with the majority fairly negative; there was an expected increase in severity, and function was expected to deteriorate. Function was very important to participants and its loss was a concern raised in all interviews, whilst pain was rarely mentioned with respect to current expectations. There was a notable use of the term 'cripple'; four individuals spoke of their expectations about becoming crippled by the condition. Expectations of function and severity were evaluated independently, for example the

condition may have been expected to get more severe, but not to the extent that a walking stick would be required:

If it stays like this I'm not gonna have any problems but these problems, these things do get worse, don't they? [05]

When I've had this knee before somebody said to me "why don't you get a stick?" but I couldn't visualise myself walking about with a stick [05]

Reasons for positive expectations were attributed to: favourable treatment expectations; seeing others with OA; having a positive outlook on life and knowing how to control the condition. Negative expectations were related to the belief that no cure existed and seeing others with OA.

Whilst some participants held readily accessible expectations, others were less certain and held what were comparable to Thompson and Sunol's 'unformed expectations', where individuals are unable or unwilling to share their expectations (Thompson & Sunol, 1995). In this study, responses to the question about the future were often given in the form of questions, rather than statements:

I'm fed up that I've got it this age, I know I'm not young but I would have thought, you know, I do feel what am I gonna be like when I'm 60 if I'm like this now? That really does get to me [02]

or individuals expressed their hopes for the future:

I'm hoping against hope that one day before I die I might be able to even to walk down the steps...even to get on the bus, even to do my housework, I can't even do my housework at the moment [25]

Some individuals stated that they had no expectations as they felt that they couldn't know what would happen in the future, and they would worry about their knee condition when they had to:

Whether it will get worse, I don't know, because you don't know what's round the corner, really do you...erm hope, I'm hoping I can cope with it as it is and I'm hoping, I **hope** it stays as it is really...but you don't know do you? [19]

I'm not thinking to myself "oh god I'm gonna be crippled up in a couple of years time", I'll cross that bridge when I come to it kind of thing [05]

In comparison to expectations about the general condition, far fewer ideas were offered concerning treatment. Only four individuals spoke specifically about expectations; three were positive, one was negative. Expectations related to necessity and efficacy of treatment, that is, the extent to which a treatment would be required and how effective it was expected to be:

Interviewer: how optimistic do you feel about [the knee pain] getting better?

Participant: well, **very**, very, because as I say erm () if er, if I'm lucky enough to get, eventually, on this erm, physio programme up at Dulwich...then I can get a bit of help there, then I'm **hoping** that I will be able to be at least 90% of my old use of my legs, and that's what I want...I'd like a hundred but I don't suppose I'm ever gonna get a hundred, but as much as I can, I would like very much to be able to do that but er () it's just a waiting game really to see what they're, what they're gonna do up there...but er () I think, myself I think that erm (3) they're () the more, more (2) exercise and the more, the more I stick to this erm Movelat rubbing in and the more I stick to this exercise and...the more I stick to that part of the programme, the more I'm hoping that I will be more agile [07]

There's not, you know, I don't feel there's a great deal of treatment...for this particular complaint [05]

Others who talked about future treatment options spoke in terms of possibilities or concerns and hopes that, for example, they might have to take painkillers, or undergo joint replacement surgery. With regards to taking painkillers there was an almost unanimous desire to manage without them, often because of concerns over the body becoming used to them rendering them ineffective, or starting other problems:

Interviewer: how would you feel if you had to take painkillers?

Participant: no I'm not a lover of that actually...I'm not, I would hate to have to resort to that...I don't like that at all, I don't mind anything like this [*points to glucosamine tablets*]...but I think, 'cos if you carry on doing that it sets off other things, doesn't it?...I'm not a lover of that actually [21]

I'm an old fashioned believer that if you start taking tablets, after the first couple of months the body accepts those tablets and they don't do any good at all [16]

4.4.2 Initial Expectations

Participants were asked to think about their expectations when their knee problems first started, or when the condition was diagnosed. More information was given for these retrospective expectations than when participants were asked what they thought would happen in the future. As with future expectations, responses could be categorised into outcome and treatment beliefs. As before, some phrased their responses in terms of hopes, concerns or questions rather than expectations, although these individuals were in the minority:

I thought I'm quite young to get, and he did actually say it's very advanced in someone my age...and I was disappointed in that um, and I began to wonder how restricted it was going to be for me 'cos I have an 11 year old boy [02]

Six individuals said that they either had no expectations or no idea what the problem was, and that they had given the condition little consideration:

I never took much notice of it really, I just thought well I think it's arthritis you know [18]

There was a fairly even split between those with positive, and those with negative expectations. People who had a negative outlook spoke about their expectations of increasing severity or progression of the condition, and about becoming crippled:

I thought well yeah, this is it, I'll be crippled, I won't be able to move [25]

Pain appeared to be a possible determinant of these negative expectations with the amount of pain experienced informing their ideas about severity and progression:

it was so painful and so swollen and I think that was then it really got to me that it was gonna get worse...and never get better, that was it [11]

Positive expectations were related to a larger number of areas. These were functioning, with ideas about independence and little reduction in mobility; little progression; it would be a temporary problem and the pain would not last for long:

I never think of [the future] you know, when they said wear and tear I thought it was something would just go away...you see I thought it was like if you've got a headache, a couple of tablets, you know, you never think, carefree, never think about **after**, always just thinking of certain moment...so I didn't really think I have something with me for years and years to come [20]

When these initial expectations were compared to current circumstances responses varied from much worse to better than expected (see figure 4.2). Those who found the condition better than expected attributed this to: having less pain; more mobility; not experiencing the anticipated deterioration, or progression being slower than expected. In addition, negative expectations that had developed through experience of a friend or family member's OA had not been fulfilled:

Interviewer: As you are now, after six years, how does that compare to maybe how you thought it would be?

Participant: favourable...definitely favourable, because I thought it was a rapid progression you know, to being completely useless on it...but it hasn't, touch wood! [16]

None of the secondary care patients considered their OA to be better than they had anticipated, and this was the only difference found between the primary and secondary care participants. Participants who found it worse than expected attributed this to having more pain, less mobility, a greater emotional impact, experiencing greater reliance on others, and the permanent nature of OA:

I tell you the truth, sometimes I sit down and I cry my eyes out...I didn't expect it to knock me [20]

I didn't think I would be sort of erm, unable to do things for myself, you know what I mean?...I never sort of...I don't like putting anybody to do anything for me [24]

Figure 4.2 Comparison of prior expectations with current situation

Better Than Expected	Worse Than Expected
<ul style="list-style-type: none"> • Less pain • More mobility • Less disease progression 	<ul style="list-style-type: none"> • More pain • Less mobility • Greater emotional impact • Greater reliance on others • Permanence of condition

As with outcome expectations, individuals gave more information about treatment expectations when they first experienced knee problems than for beliefs about treatment expectations in the future. Their expectations related to four aspects of treatment: (1) availability (2) efficacy (3) necessity (4) service issues.

Treatment Availability

A cure was anticipated by several participants and disappointment was expressed when they realised that none was available:

I was very disappointed () I thought, well there must be treatments you know, there must be something...to get this because I then thought I'm only 50, 51...and you know I thought I'm quite young to get [this] [02]

Treatment Efficacy

Most participants were able to express expectations of treatment efficacy when their condition first started or they first consulted a doctor. All these expectations were positive and related to pain relief. These beliefs came from previous experience either with their own or other's treatment:

I thought they'd give me a painkiller that worked! [*both laugh*] to take away the pain, but it doesn't do that! [24]

Interviewer: before you started [physiotherapy] did you have any ideas about whether it would help, or what it might do?

Participant: yeah, because I had physio before when I had the fall on the bus and before that with this arthritis, it wasn't this bad, I went to King's and had physio, at my hospital I had physio, I went to the Rheumatology and saw some doctor there so I had an idea, I know what it's about [26]

In retrospect most felt that their treatments had been largely ineffective in relieving pain.

Treatment Necessity

Some thought was given to how necessary painkillers or joint replacement surgery would be in the future. These treatments had been suggested by a GP and an orthopaedic consultant respectively and had been taken on board by the patients:

My old doctor...she said to me if you can put up with the pain now, she said do it...because she said later on in life you will definitely need something so it's better that you take it later on in life so that it does you more good, than now...she said because later on in life you'll have to have stronger tablets so she said your best bet, if you can cope with it now [19]

Service Issues

This final category related to aspects of treatment such as speed of appointment to see a specialist, or the amount of treatment they would receive. Again, these expectations were all positive and disappointment and annoyance were expressed that the reality fell short of their expectations:

I mean my expectation was, was erm, to get an appointment a bit quicker than I did, but, in effect, erm, I didn't, my appointment's not till next month. Realistically I suppose that's just the way things are [04]

4.4.3 Expectations of Developing OA

An issue that arose during an early interview and was raised with subsequent participants concerned the extent to which the OA had been expected. Those who expected to develop OA attributed it to age, trauma to the knee, occupation, and hereditary factors:

I suppose I really sort of expected it to be arthritis because of all the kneeling I used to do, I thought well, I'm either gonna end up with housemaid's knee or arthritis in the knees [*laughs*] so I suppose I wasn't really surprised you know, I just sort of expected it [11]

I've had a hard life being a gardener, I've been on my legs all my life one way or another, so I expected some wear in the joints... I mean you take anything that's got sixty three years of hard wear on it, it's got to give way sometime [16]

Most individuals had not expected to develop OA and were “taken aback” by it. This was due to leading what they had considered to be an active or healthy lifestyle, or because there was no family history of OA:

I was surprised when they told me what was wrong...cos I didn't know what was wrong with me, I only knew that I was in a lot of pain [24]

At first I thought “oh, it's a bit of a **critical** thing which will probably right itself... you know because there's really no history of it you know from my family, I've never known anyone end up in a wheelchair... [04]

4.4.4 Sources of Expectations

Of interest was the source of participants' expectations. The majority who spoke about the development of expectations could identify where their ideas about OA had come from. The majority had developed expectations for both treatment and outcome from others who they had identified as having OA, whereas few identified health professionals as a source of expectations about either treatment or outcome:

Seeing other people, you know, I mean that's the only way you can look at it like that, you know...by knowing other people who've got

near enough the same problem, you know...and you're walking with them and they're struggling [06]

They were going to look into the possibility of replacing the knee...and at the time they were thinking about it the chances were only seventy-thirty, so I said I'd put up with the pain, because I used to do work with the elderly and we had a young lady there, well, elderly lady that had both her knees replaced and ended up in a wheelchair, they couldn't mend her legs or anything, so I thought well I don't want that, if I can struggle around I'll carry on [16]

4.5 DISCUSSION

The overall aim of the study was to explore expectations of OA held by participants with the condition. Current expectations of outcome were primarily concerned with the extent to which the condition would deteriorate in terms of function and severity. Pain was mentioned very rarely, whilst all participants talked about their condition's impact on function, whether in terms of expectations or hopes and fears. This is possibly because pain formed part of the concerns about increasing severity, but was not the most pressing concern and could be tolerated more than reduced functioning. Alternatively they may have learnt to cope with pain and knew that they could still function with it, whereas impaired function was something they were less able to control. In addition, participants evaluated function and severity separately, so expectations of deterioration in one did not necessarily correlate with expectations in the other.

The majority of patients who expressed expectations had either positive or negative ideas about the future, and reasons, where given, were analysed for why certain expectations were held. Both groups identified observing others as a reason for their expectations, but differed in terms of where their control lay; individuals with positive

expectations held a positive outlook on life and felt able to control their condition, whereas those with negative ideas felt that no cure existed.

In contrast to future expectations, reasons for a negative or positive outlook at the onset of their knee pain did not focus on treatment or control, but on the progression or severity of the condition for negative expectations, and on retaining independence and functioning, not increasing severity and the pain and condition being acute. For both future and prior expectations a small number of patients talked about being crippled by the condition, indicating extreme ideas about the outcome of the condition, and the likelihood of it happening to them.

Compared to ideas about outcome few people had expectations about the type of treatment available to them in the future, which may have been due to a lack of “expert” knowledge. Those who shared their treatment expectations talked about the necessity and efficacy of treatment they may be offered. This also applied to prior expectations along with ideas concerning availability and service issues, such as amount of treatment. These were present possibly because they relate to expectations of a specific event, and may not be held when there is no prospect of treatment; only one participant was potentially undergoing treatment (physiotherapy) in the weeks following their interview.

A general dislike of medicines was expressed by most participants, along with a preference for avoiding them. Generally medications were viewed as unnecessary as they only affected symptoms rather than the underlying problems. Participants also held concerns related to overuse, believing that this would make the medication less

effective, and about harm and the action of the drugs (Horne & Weinman, 1999).

These concerns were unsurprising; patients often take a multitude of medications to control conditions such as hypertension and diabetes, so medications which only serve to temporarily relieve pain may be seen as unnecessary or risky in the long run.

Conversely, some participants saw analgesics as necessary even though they did not like them, because they were perceived as the only way to control pain. In work on other chronic illnesses high concerns and low necessity beliefs were related to low adherence (Horne & Weinman, 1999), including in upper limb disorders (Calnan et al., 2006).

Issues raised during the interviews also mapped closely onto dimensions used in the revised Illness Perceptions Questionnaire, which measures the way people make sense of their illness. These were; timeline, consequences, personal control, treatment control, illness coherence, cyclical timeline, identity, emotional response and causal beliefs, with the first four having direct relevance to expectations (Moss-Morris et al., 2002). This suggests that the IPQ-R is a suitable measure to use with this population.

Of particular interest in this study was the source of participants' expectations. The majority of participants' expectations were identified as coming from observations of people they had identified as having OA, whilst popular media seemed to have very little influence on expectations. Similar results were found in a study on unmet expectations of care, where only 7% identified popular media as sources of their expectations about treatment (Kravitz et al., 1996). The importance of previous experiences was also highlighted as a source of expectations, as negative encounters due to treatment ineffectiveness influenced patients' ideas about future outcomes.

The method of using comparisons with others to form expectations appears to be an ongoing process as participants also used comparisons to form ideas about the future at the time of the interviews. This suggests that even when the condition has been present for a significant length of time people are still forming and revising their ideas and expectations. This may be due to only remembering those with noticeable OA problems and may be a defence mechanism that increases positive feelings about their condition. The use of comparisons has been found in other musculoskeletal and rheumatological conditions including low back pain (Osborn & Smith, 1998), rheumatoid arthritis (Affleck et al., 1987) and OA (Turner et al., 2002). In a review of social comparison studies in cancer, Taylor and Lobel propose that upward and downward comparisons can exist simultaneously and perform different functions; downward comparisons serve as self-enhancers, whilst upward comparisons, “contacts”, are used to provide patients with information about what can happen (Taylor & Lobel, 1989). However, in this study participants used downward comparisons to form expectations for the future, i.e. they compared themselves against others who they perceived to have more severe problems than themselves.

Participants from both primary and secondary care were interviewed and transcripts analysed separately and then compared. The distinction made between the groups reflects where they were recruited from, however individuals in primary care were not excluded if they had been referred to secondary care as long as they had not previously undergone knee replacement or were on a waiting list. In addition the groups were similar on several demographic variables. Whilst the fact that they were recruited from different settings may have led to differences, the responses and themes in the

interviews were very similar. The only evident difference was that no secondary patients felt that their current situation was better than they had expected, compared to a small number in the primary care group. The reasons for this finding are unclear. It is unlikely to be a result of experience (or lack) of secondary care as some participants recruited from primary care had also been seen at a secondary care level. This blurring between treatment groups is a problem when seeking to recruit patients to a purely primary care sample; OA patients may be referred to secondary care, but if not placed on an orthopaedic waiting list (which none of these patients were) they are usually discharged back to the GP, so the study sample reflects the normal process of care in OA.

A major difficulty when conducting the interviews was encouraging participants to reveal their current expectations. The majority could express initial expectations, but only a small number spoke about current expectations and “hope” was frequently used instead and this was particularly apparent with regard to treatment expectations. Similar results were found in a study on OA patients undergoing joint replacement surgery, with participants being “generally evasive and non-committal in their replies” (Woolhead et al., 2003).

If participants feel unable to reveal cognitions or simply have no expectations about a condition or treatment, they may talk about their hopes instead, which raises the question; are patients telling us what they *want* to happen, or what they *think* will happen? This uncertainty may make the measurement of future beliefs problematic if hopes are inadvertently measured instead of expectations. The problem could be addressed by asking participants what they hope will happen with their condition, then

asking them what they think is likely to happen – this may make explicit the distinction that is being made. In the present study it is not clear whether “hope” was being used interchangeably with expectations; whether there was a lack of expectations comparable to the concept of “unformed expectations” (Thompson & Sunol, 1995); whether participants did not feel comfortable expressing their expectations; or whether they purposely did not form future expectations since their previous ideas had not been fulfilled and they did not want to be disappointed again.

Several participants said that it was impossible to know the future and therefore they did not hold any expectations about either treatment or outcome, but dealt with any problems as and when they arose. These beliefs relate to the construct of consideration of future consequences (CFC) (Strathman et al., 1994); low CFC individuals attach importance to short-term consequences, whilst high CFC individuals focus more on long-term consequences. In a study on effective communication in a new colorectal screening programme low CFC individuals were more receptive to messages that focused on positive short-term consequences and long-term negative consequences, whilst for high CFC participants the opposite was found (Orbell et al., 2004). Low CFC individuals who expressed negative thoughts about screening did not want to consider the possibility of developing cancer and were happy to ignore the issue. Because self-management is important in OA, these findings may have important implications for self-management messages – if low CFC individuals only pay attention to (negative) short-term consequences such as increased stiffness or time demands, they may be less likely to alter their behaviour, e.g. exercising or buying healthy food. Further work could examine future consequences in OA and how these beliefs affect interpretation of OA-related messages.

Prior expectations were much more readily expressed than future expectations and differed from future expectations in terms of the emphasis on pain and function; these ideas focussed much more on pain, which was often seen as an indication that the problem would be chronic. Previous studies in gynaecological cancer and knee replacement found participants at post-operative interviews were able to describe their surgical experience in relation to pre-operative expectations, despite not expressing any expectations at the pre-operative interview (Haas, 1999; Woolhead et al., 2003). This again suggests that some people's expectations are latent or not fully formed, or they have ideas but do not wish to share them, perhaps for fearing of making them happen.

Further work should explore the relationship between hopes and expectations (and the extent to which they overlap), which is more influential in terms of outcomes, and also look at whether individuals who express no expectations differ from those who *do* have expectations.

In this study participants evaluated function and severity independently, and also identified several factors relating to treatment expectations. These important findings indicate a need in quantitative measurement for multiple questionnaire items covering several aspects of a condition or expectations, rather than a single global item, which is how expectations data are often collected. Further research needs to be conducted on global ratings to see how closely they correlate with specific measures of both function and severity, and also to determine how much function and severity overlap.

Pain appeared to be a stronger influence on participants' early expectations (when they first developed knee pain) than for their current expectations. This suggests that the influence of symptoms may change during the progression of the condition i.e. pain is more central in the early stages of the condition, but as the individual adapts to the pain, and function deteriorates, issues around function become more salient. A longitudinal study would be required to rule out the possibility of recall bias, and would enable further exploration of this issue.

The prioritising of functional difficulties above pain was also found in interviews with other OA patients (Turner et al., 2002). This merits further investigation as it may contradict what is expected by healthcare professionals, who may be prioritising treatment of pain over maintenance of function. Discussing patient priorities may increase patient satisfaction with management and in turn increase adherence to treatment regimens.

Participant beliefs mapped quite closely onto constructs of the BMQ and the IPQ-R. This supports the use of these constructs in knee OA and lends weight to the extended model (Horne & Weinman, 2002). Future work could apply this extended model to OA and examine the contribution of the components regarding predicting outcomes and behaviour, and exploration of medication beliefs in OA patients would be of interest, to establish how similar they are to other conditions, and whether they explain medication use in this chronic condition.

The formation of expectations from observations of others with OA and from experience of treatment has direct relevance for health education; if people base their

beliefs on public health messages this may be a fruitful approach for disseminating information about issues such as self-management. Future work could investigate, using quantitative methods, whether findings still hold with a larger sample. If so, this could open up the way for the use of peer educators; individuals with OA who are trained to answer questions, address concerns and demonstrate self-management techniques. Similar approaches have shown improvements in mental health for elderly Turkish immigrants (Reijneveld et al., 2003) and increased satisfaction and knowledge in attendees at a rheumatology outpatient clinic (Branch et al., 1999).

For this particular study it was convenient to recruit individuals with established OA, but to investigate fully the formation of expectations in OA participants would need to be recruited at the onset of knee pain and followed up at regular intervals. However, recruitment of participants in this way may be problematic and time consuming, and it is possible that simply asking participants at baseline about their expectations (particularly those who were uncertain) may cause them to form expectations by follow-up, although it is unclear whether this is the case, and how it should be addressed remains a challenging issue.

These findings on sources of expectations suggest the need for an extended role for health professionals, particularly GPs who are often the initial point of contact, in educating patients about OA. This may involve counterbalancing the unnecessarily negative expectations that patients may form, and also increasing awareness of the possible outcomes and available treatment to avoid unrealistic or excessively negative ideas. In addition to increasing patient understanding of their condition, by discovering peoples' ideas about their condition and gaining an understanding of peoples'

expectations individual beliefs can be addressed which may play an important role in future health behaviour.

The use of downward comparisons suggests further education is required to inform patients about the variability of OA; not everyone will become wheelchair-bound or experience severe pain. Whilst downward comparisons may have a self-protective function, there is a danger that people will only attend to those with more serious and noticeable OA, thereby forming mainly negative expectations, which may hamper their coping and self-management abilities. Future work on the role of these comparisons in OA and their development over the course of the condition would be useful.

There were several limitations to this study. The interviews were relatively short, lasting on average 21 minutes, which was due in part to participants' reluctance to express their expectations. Some participants also found it difficult to think of things to say in relation to their condition; as they perceived it OA was part of the ageing process and little time was spent thinking about it. In this cross-sectional study participants were asked about expectations from the onset of their knee pain, which may have resulted in bias and inaccurate recall, but they were readily able to express previous expectations and a range of ideas was offered. In addition, several felt that their current condition was worse than expected, suggesting they could recall previous expectations. The longitudinal interview study reported in chapter 5 allows for more meaningful comparisons between baseline and follow-up expectations.

This chapter described the findings from cross-sectional interviews primarily concerning expectations. The development of an expectations measure, using the findings from this study, is described in chapter 6, and the influence of expectations on behaviour is explored in chapter 7.

CHAPTER 5: LONGITUDINAL INTERVIEWS

5.1 INTRODUCTION

5.1.1 Background

Many chronic conditions have a variable course, with patients experiencing changes in levels of pain and functioning over a period of time. Longitudinal methodology is used to enable comparisons between time points and to assess changes in variables, and is seen as the gold standard of research methodology, particularly in randomised controlled trials. However, longitudinal quantitative methods have disadvantages; much of the richness of patient experiences is lost as data are reduced to either dichotomous or scale responses, there is little opportunity for individuals to explain their responses to questions and limited scope for exploring patients' feelings about changes.

Longitudinal qualitative methodology is an effective means of looking in detail at changes that may be occurring, and people's feelings about these changes. It also enables individuals to look back and reflect on perceptions or expectations expressed at previous interviews. To examine the changes in the transition to motherhood four women were followed through their first pregnancies and into their first five months as mothers using interviews, diaries and repertory grids (Smith, 1999). This methodology allowed the researcher to collect extensive, detailed data, and identify the major changes occurring in social roles as the women moved from the external, public world, to the more local world of family and friends.

Few qualitative studies have examined changes in expectations over time. In participants interviewed before and after undergoing surgery for gynaecological cancers, differences

were found between aspects of care which exceeded expectations, for example pain relief, and those where expectations were not met, such as levels of staffing (Haas, 1999). Semi-structured and in-depth interviews were conducted with cardiac patients about expectations and satisfaction prior to hospital admission and again prior to discharge. Some expectations remained stable, whilst others changed and became irrelevant following information from the patient's doctor (Staniszewska & Ahmed, 1999).

Whilst these studies provide important insights into patient beliefs, they examine expectations of specific, discrete events. The likelihood of individuals with a chronic condition such as OA undergoing surgery is small, and on the whole, they self-manage their condition. Longitudinal, qualitative research is required on patient perceptions of their condition over a period of time when the treatment received is relatively stable.

In addition to looking at a specific area such as expectations, it is also necessary to examine what it means to live with a chronic condition. Surprisingly, for such a widespread condition, qualitative studies on OA generally focus on a specific aspect, such as treatment, knee replacement, coping etc. Previous work on the experience of living with OA when not anticipating a major surgical intervention has been limited. One of the few studies to do this found participants' main concerns to be pain, problems with mobility and frustration due to disruption of activities (Turner et al., 2002). This type of qualitative work can provide a greater understanding of patients' needs.

5.1.2 Study Aims

Semi-structured interviews with a small group of individuals with OA at two time points; baseline and approximately 12 months later were used to explore two main areas: the extent to which individuals' conditions and their expectations and perceptions of the condition change over time; the phenomenon of living with OA.

5.2 METHODS

5.2.1 Participants

A subgroup of interviewees from the cross-sectional interview study described in chapter 4 (see section 4.2.1) were selected for follow-up interviews. They were chosen to provide a representative balance of women and men, and a range of severity of OA. Only primary care patients were contacted for follow-up interviews as it was easier to re-establish contact with the GPs than with consultants of the secondary care patients, and therefore to contact their patients. In addition, little difference was found between primary and secondary care participants in the baseline interviews.

GP practices were contacted to ensure that they were still willing to participate, that patients were still residing at the same address and that, to their knowledge, there were no reasons why they could not be approached, such as the recent development of a serious illness. None of the practices refused or identified any patients who should not be contacted. The patients were then contacted by post, with a covering letter from the author, an information sheet, a reply slip and a stamped, addressed envelope. As in the cross-sectional study, participants could either return the reply slip or contact the researcher by phone. The information sheet was the same as that used in the cross-

sectional study, but the covering letter explained the reasons for interviewing participants a second time (see appendix 1).

Ten of the original 26 participants were contacted, a sufficient number to provide a range of experiences, without the data becoming unmanageable (Smith, 1999) (see section 5.2.4). Eight individuals agreed to take part, one did not reply and one was unable to participate due to caring for sick relatives. Table 5.1 shows the demographic characteristics of the participants and non-participants. Compared to the participants in the cross-sectional study, these patients were slightly older, with a mean age of 74 at baseline compared to 72, and a slightly lower percentage of females (63% compared to 69%).

	Participants	Non-participants	All Contacted
Number	8	2	10
Mean Age	74 (Range 64-84, SD 6.62)	75 (Range 62-88, SD 18.39)	74 (Range 62-88, SD 8.48)
Female	5	1	6

Table 5.1 Demographics of participants and non-participants

Table 5.2 provides information on each of the eight participants, all names have been changed to ensure confidentiality.

Name	Age at 1st interview	Approximate disease duration (years)	Time between 1st and 2nd interviews (months)	Place of interview
Eric	78	7	14	Hospital
Arthur	76	5	13	Hospital
Patricia	73	35	12	Hospital
Anna	68	36	14	GP practice
Peter	69	6	14	GP practice
Veronica	84	3	15	GP practice
Lucy	79	10	13	GP practice
Louisa	64	32	13	GP practice

Table 5.2 Participant details

5.2.2 Ethical Approval

Ethical approval to approach and interview participants from the cross-sectional study for a second time, was granted by the King's Healthcare Research Ethics Committee (see appendix 1).

5.2.3 Procedure

The mean length of time between first and second interviews was 14 months. Five interviews were conducted at the patients' GP surgery and three were conducted at the hospital, when this was more convenient for participants. Eric asked that his wife be present during the interview; for all others only the researcher and interviewee were present. Informed consent was obtained for the interview to be audio-taped, any questions were answered before the interview commenced and a copy of the consent form was sent to each patient for their records. The interview schedule was similar to that for the cross-sectional interviews, to allow for comparisons between the two

interviews. However, participants were asked specifically to compare their present condition with a year ago, and to identify any changes they felt had occurred.

Prior to each follow-up interview the transcript of the previous interview was re-read and notes were made on key points, such as participant expectations, the main problems with their OA, and ideas about medications. This acted as a prompt if individuals were unable to recall the severity of their condition or their most pressing problems at baseline. It also allowed the interviewer to ask about particular themes that arose during the first interview.

All interviews began with a general opening question, such as “can you tell me how your knees are at the moment?”, although there was no fixed order to the interview schedules (Haas, 1999). The interviews lasted 20 minutes on average (ranging from 11 to 39 minutes). The interviews were transcribed by an experienced secretary and the transcripts were then checked by the author. Transcription notations are given in appendix 2.

5.2.4 Analysis

Idiographic interpretative phenomenological analysis (IPA) (Smith et al., 1999) was used to analyse the data. In idiographic IPA each participant or case is initially treated separately, and because of the equal commitment to each participant and detailed analysis, a small number of participants is preferable (Dean et al., 2005). Only later in the analysis are the other transcripts incorporated. Separate master lists were produced for each transcript and similarities were then looked for across participants to produce one table of master themes.

Each participant's set of transcripts was analysed separately. The baseline interview was read through several times to ensure familiarity with the contents. Keywords for important segments were noted on the left hand side of the margin and then listed with line numbers for easy reference. When this was complete the transcript was read again, looking for groupings of keywords. The analysis is an interpretative process and to ensure that the researcher's views did not bias the analysis, the original material was constantly referred to.

The major themes were then listed in a table of master themes (Smith et al., 1999) to allow links between different themes to be clearly illustrated, for example between treatment and self-management or between mood and the future. Once the baseline interview was complete the procedure was repeated for the follow-up interview (see appendix 2 for example). The tables of master themes were then compared between the two time points to look for similarities and differences between themes which emerged. In addition, participants' expectations and any related data at each time point were extracted from the transcripts to allow analysis of any changes over time.

A second researcher analysed four sets of transcripts, chosen at random, to check the validity of the author's themes. Once the second researcher had generated her own sets of themes, these were compared with the author's and no major discrepancies were identified.

Once summaries with master themes were completed for each participant, themes between individuals were compared. When analysing the data for themes about living

with OA, both baseline and follow-up transcripts were used to increase the richness of the data, as both included reports of living with the condition. This process involved moving between each set of master themes and the original transcripts to ensure that themes were present in the original interviews. Because of the cyclical nature of the process, emerging themes may be dropped at a later stage and replaced with other themes if there is not enough supporting evidence from the transcripts.

5.3 FINDINGS

5.3.1 Changes over Time

Comparisons of the master themes allowed the identification of differences at baseline and follow-up in expectations about the condition and treatment, other beliefs and in the condition itself.

When baseline and follow-up conditions were compared, two participants, Arthur and Lucy, experienced major positive changes in their situations between the two interviews; Lucy was now experiencing only occasional mild pain and had not needed to take any analgesics since the previous interview, which was unexpected:

Well, at this very moment they're okay. No pain, no nothing. So I'm quite happy with myself really, you know. And, as I say, I haven't taken any pills so, you know. But now and again when I've been in the garden and the weather is really strong, the heat is so strong, then they **do** hurt a bit, but not a lot, not a lot. So I'm quite lucky. [Lucy, follow-up]

Arthur was the only participant who had received an intervention during the time between baseline and follow-up interviews, which he had found very beneficial. His improvements were seen in his perceived ability to manage his condition:

I mean, you know, when you look at it, you think to yourself: I'm never going to do that! But after that, you can do it! And that's

what I'm saying; it gives you confidence – that's the word,
'confidence' to do it...And, you know, they point out the 'rights'
and the 'wrongs' of things and what you can do and what you can't
do. But they don't teach you that, they teach you what you can do
[Arthur, follow-up]

By the second interview both participants had a more positive outlook than at baseline, possibly because their perceptions of the knee pain had changed in a way neither were expecting:

I: And, again, when I last saw you, you were worried that in the future you might be more incapacitated than you **were** with the knees. Is that something that worries you **now** () or?

P: Well, not now - well, not now in the respect of **worrying** about it. I just think to myself: Well () every day is a different story
[Arthur, follow-up]

Hopefully, if I carry on as I'm doing now, they won't be much worse. They might be a little bit worse because I shall be a year older, won't I! Then, but, hopefully, I don't think they will be
[Lucy, follow-up]

Both participants' views on treatment had also changed by follow-up, again this may be due to changes in the condition. For Arthur, the prospect of knee replacement seemed less of a possibility in the future:

But as far as the **knee replacement** for me, I would debate about it but I'd have to be in a lot more pain than I'm in now...But as I say, I would like to try other things before I go to that extent.
[Arthur, follow-up]

And Lucy now perceived herself as being able to manage without medication:

I'm quite chuffed with myself really. And I'm very pleased that I did away with those tablets. Very pleased. And I mean, if, say, by the time next year comes I have to start taking a Panadol now and again, well I shall reluctantly take one but I will rather than go through diabolical pain [Lucy, follow-up]

Peter was the only participant whose expectations and condition had become more negative by follow-up. At baseline, although he had problems with his knees, for him, other health problems were more significant:

I: but in terms of the knees you have a fairly, fairly sort of favourable outlook?

P: yeah, yeah...it's the left leg worries me more now because the arteries are closing...and I think that is more of a () shall we say, erm, it's got more potential for harm in the future than the arthritis has...I mean if that started to progress then I would start getting really worried, I mean they say that if it progresses they will put a shunt in and things like that, but that would worry me more than the arthritis would, because I've had the arthritis long enough now to know that I can control it [Peter, baseline]

However, in the intervening year, his knee pain had worsened significantly, causing him as much concern as his other problems:

P: They seem to have got quite a bit worse, I'm finding a lot of problems coming downstairs, especially if I've been out for the day somewhere or I've been sitting for quite a length of time. They just don't want to seem to support me **coming down**. Going **upstairs** is not too bad. And the shoulder has certainly got a lot worse.

I: Right. How are they in terms of pain?

P: Really bad at times.

I: Right. Compared to how you were last year, how do you think you are now, or how your **knees** are?

P: I think in a scale of 1-10 I think they've gone down to about 5 now, and they were 9 last year basically [Peter, follow-up]

I: And again, last time I saw you, you felt that your leg would give you more problems, perhaps, than the knee. Is that still the case?

P: No, I think it's 50:50 really [Peter, follow-up]

As with Arthur and Lucy, the changes Peter had experienced in his condition were the opposite to what was expected. By the follow-up interview his expectations had changed in line with his condition:

I: The last time I saw you as well, you felt that it was unlikely that you would need a knee replacement in the future. How do you feel about that now?

P: That is becoming more likely. I mean if, for example, after this holiday, that I **don't enjoy** it, then I might seriously start to consider. Because walking is my enjoyment really – not sitting on a beach sunning myself, I'm too old for that game! [laughter]

I: With the changes in the knees that have happened in the last year, I mean in addition to the knee replacement or the thoughts on that, has it had any effect on your ideas about what might happen in the future with the knees?

P: No. Except that, as I say, it may come to the stage where I will have that knee replacement, that's the only thing. I mean I can

obviously see now, with hindsight, that it is **not** going to get any better; it **won't** get any better. Even with drugs, I mean it will only **subdue** the pain; it won't do any miracle cures or anything like that

I: Did you think at any time point that it **would** get better?

P: I thought it **might** do [follow-up]

In addition to the changes in his condition and expectations, a change was also seen in Peter's views on treatment and his criteria for accepting treatment; function was still important but pain was now a crucial factor, and he was considering joint replacement surgery:

I: How bad would the pain or just how bad would the knees have to be for you to take pain-killers?

P: Inability to walk **completely**...I mean if I found that even a short distance was getting too painful, then I would probably try Paracetamol, and if that didn't work, I would probably go back to the doctor to get a joint-reducer or something like that [Peter, baseline]

I: What was it that kind of made you think about that [joint replacement surgery]?

P: Just the sheer pain factor really...I mean beforehand the pain was, I suppose on a scale of 1-10 it was 2 or 3. And it's now gone up to sort of 4 or 5 – maybe even up to 6 now...perhaps at some stage it would have to come to that [Peter, follow-up]

The remaining five participants showed little change between interviews in either the direction or strength of their expectations:

I: how do you think it will be in maybe a couple of years time () do you think that there'll be any change, or?

P: I suppose there could be, it could be worse [*laughs*] I mean you just don't know do you?... you just don't know what's going to er, to happen really I mean er, I mean if it stays like this I'm not gonna have any problems but these problems, these things do get worse don't they?...I'm not looking, I'm not thinking to myself "oh god I'm gonna be crippled up in a couple of years time", I'll cross that bridge when I come to it kind of thing [Patricia, baseline]

I: So have there been any changes or are there changes you can think of in terms of the kind of **picture** that you have of Arthritis in terms of how severe it might get, or treatment, or what might have caused it?

P: No, I don't think there has. Because I suppose in a way I've not thought about it! [*laughter*] Not thought about it in that respect! Oh well, if it gets that bad, I'll cope with it when it **gets** that

bad!...You know, I think to myself: Well, why build up a picture of something which might never happen, really!...I mean, if you said to me: “Well, in five or six weeks time you’re going to be really bad,” well then I might **start thinking** about it! [laughter] But, I mean () why worry about something which might never happen, really! [Patricia, follow-up]

Where changes in these participants’ conditions occurred, they were in the expected direction:

I probably see it maybe getting worse...unless they can find some easier painkillers or something that could **really kill** the pain but I doubt it...but right now I feel that maybe it getting worse [Louisa, baseline]

P: I mean as I’m getting older, the pain is **still** getting a bit worse! [laughter]

I: So you feel that it’s getting a bit worse?

P: Yeah. I think to **me** it’s just () I don’t see the difference from the last time...it just feels a bit worse, it hurts...they feel a bit worse than before. But they **still** hurt all the while really bad. I think the body’s getting old [Louisa, follow-up]

5.3.2 Living with OA

The following section describes prominent themes that emerged from the interviews, concerning living with OA.

Table 5.3 illustrates the major and sub-themes. The following section focuses on the themes concerning uncertainty, coping and the future.

Master Themes	Sub Themes
What is the problem and what can help?	<ul style="list-style-type: none"> • General condition • Available treatment • Self-management
Managing the symptoms	<ul style="list-style-type: none"> • Necessity and concerns • Uncertainty • Criteria for accepting treatment • Ways of taking medication • Perceptions of treatment
Not just a physical problem	<ul style="list-style-type: none"> • Experienced emotions
What the future holds	<ul style="list-style-type: none"> • Expectations • Hopes • Fears
Looking after the self	<ul style="list-style-type: none"> • Coping strategies • Self-efficacy • Mind over matter

Table 5.3 Master themes

5.3.2.1 What is the problem and what can help?

The most prominent theme to emerge concerned uncertainty, which related to three areas: the condition in general; available treatment; self-management.

General condition – This area concerned the nature of the problem, the cause, and how objective measures such as x-rays related to subjective indicators such as pain:

P: I was almost expecting you to say: “Oh look,” you know, “this [x-ray] is terrible, and **that’s** terrible!” But I don’t know what I thought because I mean I’ve never () you look at it, and you explained what little **you** knew about it, and I think to myself: “Well that’s alright!” I think I expected to see something quite () a totally disjointed knee! [laughter] But it’s not like that at all!

I: And what kind of made you expect to see () that?

P: I suppose it’s just because of the **years** I’ve had the pain there, you know [Patricia]

There was also uncertainty about the future in terms of duration, progression and variability i.e. not knowing what would happen on a day to day basis:

Some days it’s worse than others, and some days you think to yourself: “Well, I wonder why?” Yesterday it was like this and it was painful - or **more** painful - but today it’s **tolerable**; you can tolerate it. And that’s how you’ve got to carry on...if the pain is strong one day, then I do the normal thing, that is I still try and walk and try and do things. And then I...before I go to bed, I’ll have a bath and I’ll rub it in. And then the next day I wake up and it’s tolerable; you can manage it. And you say to yourself: “Well, I wonder why **yesterday**...?” [Arthur]

Treatment – some participants felt that there had been a lack of guidance or advice from health professionals, which resulted in uncertainty regarding treatment availability:

I: In terms of sort of information you've been given over the years about managing the knee pain, sort of coping with the arthritis, erm, how's that been?

P: very poor...I think that if there was **someone** like, I don't know, not necessarily a nurse or someone like that, who could either give you a booklet say well look, if you do this it will be this if you'd done that, it would, you know, some sort of description of **how** you're gonna manage it...**is** there anything that you **can** do? Would putting it up in the air be better than sitting it, things like that, that's far better explained...instead of saying you've got osteoarthritis, have a course of physiotherapy, take ibuprofen or any other drug you want to, that's it, it's not really () I mean I like to be () if you like dot my eyes and toes, have it really fully explained how but I mean nowadays they just haven't got time [Peter]

The lack of guaranteed success in relation to surgery was raised and was putting patients off the idea of a knee replacement:

They said that it would be a possibility, they were going to look into the possibility of replacing the knee...and at the time they were thinking about it the chances were only seventy-thirty, so I said I'd put up with the pain, because I used to do work with the elderly and we had a young lady there, well, elderly lady that had both her knees replaced and ended up in a wheelchair, they couldn't mend her legs or anything, so I thought well I don't want that, if I can struggle around I'll carry on [Peter]

Uncertainty about medications, including their action, and the possible effects or damage, was raised by several participants. There was also some concern about the development of new treatments, and how recipients could know whether or not they would be effective:

The point is that how many, how many tablets can the body take without rebelling somewhere along the line or without erm causing other problems like, you know? That's what goes through my mind because er, as I say it's...it's a thing that when you hear people taking, like my wife she takes a lot of tablets but when you hear people taking a lot of tablets and you say to someone in the medical profession "well when, how do these tablets know which way to go?" they've got to do a lot, they say "well they find their own way", but you've got to ask yourself how long does the body go on like this, finding their erm, with all these chemicals going round your body and finding their own way [Arthur]

Self-management – reassurance was sought at both time points about whether self-management strategies were appropriate:

I went to the doctor here and she gave me ibufen gel for the right one, to rub that in...night and morning, that's alright isn't it?
[Veronica]

I: erm, have you had any sort of other treatments such as physiotherapy?

P: no, no, no, none...would other treatment do it better, the physiotherapy?...it might not

I: it might do, I mean you sort of said that you do exercises at the moment

P: yes, yes I do, that's okay is it? [Veronica]

5.3.2.2 *What the future holds*

Participants talked about the future in three ways: expectations; hopes; fears.

Expectations – whilst some participants tried not to think about the future, or said they had no expectations, positive expectations were expressed, for example a knee replacement was seen as unlikely or they were unable to visualise themselves with a stick:

I: And how would you say your outlook is now, in terms of the arthritis?

P: well it's not getting, hopefully it's not getting worse...but it's really sort of stable, I think at the moment...but whether it will get worse, I don't know...because you don't know what's round the corner, really do you...erm hope, I'm hoping () I can cope with it as it is and I'm hoping, I **hope** it stays as it is really...erm, but you don't know do you? [Lucy]

P: I hope I won't have a zimmer frame or a stick! [*both laugh*]

I: but you don't feel that's very likely

P: well, funny enough when I've had this knee before somebody said to me "why don't you get a stick?" but I couldn't visualise myself walking about with a stick, I mean I, I'd really have to be very bad [Patricia]

Others expressed negative expectations, feeling that deterioration, particularly linked to ageing, would occur, and that at some point they would be unable to move, the condition would be unlikely to improve, or a stick or surgery would be necessary:

It may come to the stage where I will have that knee replacement, that's the only thing. I mean I can obviously see now, with hindsight, that it is not going to get any better; it **won't** get any better. Even with drugs, I mean it will only **subdue** the pain; it won't do any miracle cures or anything like that [Peter]

However, as discussed in chapter 4 (section 4.4), it was often difficult to get participants to talk about their expectations, and instead they talked about their hopes and fears more frequently.

Hopes – these included improvement in the use of the knees (which relied on participating in an exercise intervention), and that deterioration would either be a slow process or would not occur, i.e. the knees would remain stable:

I'd hope it would ease and that I wouldn't be able not to do anything, you know?...that I would still keep going...I wouldn't be like crippled up...so that's always at the back of the mind...it's at the back of the mind now that they're not gonna give up completely so that I can't walk...and er, so I've tried to keep going [Anna]

Fears – participants were concerned about mobility, the knees “giving up”, and not being able to walk:

I get very depressed about it and I can sort of see myself, it's in my head really, I think oh gosh you're going to be on sticks or gonna be in a wheelchair or something [Anna]

The hopes and fears addressed very similar issues, notably that of problems with function, emphasising the importance participants placed on this.

5.3.2.3 Looking after the self

This theme encompassed a wide range of thoughts and strategies, broadly categorised into coping and self-management strategies, self-efficacy and mind over matter.

Coping strategies – figure 5.1 shows the coping strategies used by participants.

<ul style="list-style-type: none">• Perseverance/not giving in• Acceptance• Adjustment• Controlling the condition• Putting up with it• Not taking liberties	<ul style="list-style-type: none">• Living with it on a day-to-day basis• Distraction techniques• Not thinking of the future• Remaining cheerful• Focusing on what an individual can change
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Figure 5.1 Reported coping strategies

Perseverance was the most frequently mentioned coping strategy, and participants identified this as an important way of managing the condition:

I'll be 66 next month and I'm not giving up yet! So I've still got my couple of years to go yet!...As long as I can move around, and I'm moving. It's not going to hold me down!...On the 23rd of next winter I'll be 66, so I'm still going around! There's no way it'll get me down! [Louisa]

We just live for the next day and carry on the same as the day before and just carry on...because if you're going to let it **beat** you, then you **will be**...well, if you like, you will be a lump of wood, won't you; you'll be sitting in the chair doing **nothing**. And then when you do that, your **mind** goes! And when your **mind** goes, well you might as well you might as well go altogether, mightn't you? [Arthur]

In addition, participants identified several self-management strategies that they used. These included: exercise; resting; taking medication; weight loss; avoiding problem foods; pacing activities, mobilising; strategies when travelling:

I've done a pain management course for my leg at the hospital. And the general consensus of opinion is: **Do** what you want to do - and if it becomes too much, sit down for five or ten minutes. If you're going on a long walk, for example – ten miles or something like that – sit down for ten or fifteen minutes. Instead of doing it in one hit, do it in three or four. And that's how I'm basically trying to **use** it without **abusing** it, if you like [Peter]

Self-efficacy – related to coping and self-management strategies was self-efficacy. Participants talked about their ability to control the condition (e.g. by exercising or avoiding problem foods, and the amount of confidence they had in their own abilities:

I feel, to be honest, on top of the world, because I **know** how to treat myself now without a problem [Lucy]

It [the exercise programme] just turned round and gave me the confidence to know that I can carry on doing what I **have** been doing. As I say, a bit of gardening, and all the other little bits and pieces. I mean there's nothing like just sitting in a chair and thinking: Oh God, no! I can't do this! I can't do that! – You **can**!
[Arthur]

Mind over matter – Several participants identified their mental approach as important, in terms of the way the condition is perceived, mental pain versus physical pain, and what patients think they can or cannot do:

I think, because as I say, you **can** get pain, really, without it being, as I say [laughter], some of it's **up there**, as well, isn't it [points to head]?...And, I suppose, perhaps I've had this for such a **long** time, perhaps I've sort of, it's just **stuck there**. Perhaps I'll need to get rid of it! [laughter] [Patricia]

There's nothing much I can do so I just have to live with it...That's 'make believe' that: Oh it's not there! But then it **is** there! In your mind you know it's still there, but you have to just sometimes pretend: Oh it's not there! [Louisa]

5.4 DISCUSSION

Longitudinal qualitative interviews were conducted to enable an examination of changes over time in participants' conditions, expectations and other condition-related beliefs. Variability was seen in terms of participants' perceived conditions and the direction and strength of their expectations. Where little change in the condition had occurred, or changes occurred in the expected direction, perceptions and expectations remained stable. In participants who expressed uncertainty about the future at baseline, expectations tended to develop in the direction of changes in the condition, although some reluctance to contemplate the future remained. However, when changes discordant with baseline expectations were seen, follow-up beliefs developed in line with these changes. The findings indicate that beliefs are both stable and malleable; they change in reaction to new information and perceived physical changes, but in these participants this only occurred when the changes went against expectations.

This study demonstrates the potential benefits of providing patients with self-management information; the two participants who received guidance changed their behaviour and found great improvements, subsequently changes in their follow-up expectations were also seen. Previous qualitative studies with cardiac (Staniszewska & Ahmed, 1999) and head and neck cancer (HNC) patients (Llewellyn et al., 2005) also reported changes in expectations following information provision.

The perceived need for medication and knee replacement surgery appeared to change in response to changes in the condition, however feelings towards treatment did not, so whilst functional deterioration may increase the perceived need for knee surgery, reluctance to undergo the procedure does not decrease. This supports the Self-Regulatory Model (SRM, Leventhal et al., 1980), which proposes that cognitions and emotions are of equal importance and are processed separately, and suggests that in OA, emotional representations may be more influential than cognitions. If cognitions and emotions are acting independently, as these findings suggest they are, they should be measured accordingly so that their individual effects can be determined. Studies focusing on their relative importance in making treatment decisions, and how provision of information influences these decisions, will help to unpick their influences and enable the development of interventions to improve patient outcomes by addressing both emotional and cognitive representations.

Work extending the SRM (Leventhal et al., 1980) by incorporating beliefs about treatment has started to examine how different beliefs interact (Horne, 1999) and these

findings lend support to this approach; in these participants changes in the condition appeared to lead to changes in perceived necessity of treatment.

Because expectations appear to change in response to new information, not only should baseline expectations and their influence on outcomes be examined, but also expectations following interventions, to understand the extent to which they are affected. However, the presence of positive or negative expectations cannot be assumed; some participants expressed uncertainty about several aspects of their condition and important outcome differences may exist between those who hold strong ideas and those who do not.

The second part of the analysis examined themes which emerged around the phenomenon of living with OA. The strongest theme concerned uncertainty, which is unsurprising as OA is a condition with a variable trajectory; what can become extremely severe in one individual remains mild in another and the condition can also vary on a daily basis. In addition OA is a condition with minimal intervention from healthcare professionals, so patients have few opportunities to seek guidance or ask questions and this was reflected in the interviews.

Uncertainty was seen across all aspects of the condition, both in ‘global’ and ‘specific’ expectations, e.g. the general condition and self-management (Llewellyn et al., 2005), which emphasises the need for greater information provision: the participants in this study had lots of questions, particularly concerning optimum self-management and treatment, such as the action of medications. It is unclear how much the uncertainty would be reduced by providing more information, but it may help to reassure patients

and increase their self-management ability (McGregor et al., 2004). The level of uncertainty also raises methodological issues about the measurement of expectations and suggests that, particularly in studies where a “don’t know” option is not provided, expectations may not be measured accurately.

When participants spoke about the future, it was generally in terms of hopes and fears, rather than expectations, which supports the concept of possible selves (expected, hoped and feared) (Markus & Nurius, 1986). When challenged, participants were able to indicate their perceived probability of specific fears occurring. As discussed in section 4.5, focusing initially on hopes and fears, then asking about the perceived likelihood of them happening may be a way of encouraging participants to reveal their expectations and ascertaining the difference between what they think will happen and their hopes and fears (Haas, 1999).

A range of negative emotions was reported by participants with frustration (mainly concerned with function), particularly prominent, supporting previous findings on emotional impact in OA (Turner et al., 2002; Penninx et al., 1996). Participants identified a number of coping strategies to manage their OA, the most popular being perseverance. Most of the strategies were emotion-focused, rather than problem-focused (Lazarus & Folkman, 1984) suggesting that they felt few alternative strategies existed, and may reflect the lack of treatment options perceived to be available to them. OA is often seen as a minor problem, but it can have a wide-ranging impact, and improving patient coping strategies may improve psychosocial outcomes (Keefe et al., 1990).

There are several limitations which should be considered when interpreting these findings. All participants had co-morbidities which affected their mobility, caused them extra pain or involved them taking medication, which could have affected their perceptions of analgesics and necessity of different medications. Participants were asked to think specifically about knee OA and were selected so that knee pain was their major complaint, but it was inevitable that other problems may have had an impact. However, this reflects the general population of OA patients, as older adults often have several co-morbidities.

Few studies have conducted interviews at several time points, and when comparing interview transcripts from different time points it is difficult to know whether it is participants' beliefs that have changed, or the way they talk about their condition. However, reading baseline transcripts allowed participants' previous thoughts to be identified and addressed during follow-up interviews and the transcripts showed a great deal of consistency, despite a gap of at least twelve months between the interviews.

No published papers using IPA longitudinally were identified. Because of the amount of data generated and the complexities of working across several sets of transcripts, other qualitative methods may be more appropriate for longitudinal studies. However, being able to examine patient perspectives on, for example a chronic condition, and how these develop over time would be very informative.

Frequent criticisms of qualitative methods concern the subjective nature of interpretation and the issue of generalising findings from a small sample to the wider population. In this study, fifty percent of transcripts were analysed by a colleague to try

and ensure agreement in the analyses, and the findings should be seen as a good starting point from which to further examine how expectations react to new information or changes in a chronic condition.

This study examined the relationship between patient expectations and conditions over a period of approximately a year. Variations in changes in both condition and expectations were seen across participants and expectations appeared to be malleable, responding to changes in patient perceptions of their condition and to new information. Providing education and information, particularly regarding self-management may modify expectations and change behaviour. It is also important to recognise that changes occurring in a patient's condition may have an impact on their ideas about treatment, i.e. it cannot be assumed that once a decision is made it will remain the same. Further work should explore the most effective way of providing information and modifying unnecessarily negative expectations, and the most accurate way of eliciting and measuring condition and treatment expectations.

5.5 REFLEXIVE ACCOUNT

The interview and analysis process raised several interesting issues, which are worth reflecting upon. The interview process was initially quite difficult; participants commented that having attention focussed on their feelings about their knee pain was unfamiliar to them, and I was asking them to think about things they had not previously considered. Finding prompts and ways to draw out responses was difficult at first but became easier as time went on, and the second interviews with participants felt more comfortable as a rapport had already been established.

To some extent the location of the interviews and my perceived role may have initially been difficult for participants; the majority of interviews were conducted in their GP surgery so there may have been concerns about confidentiality, and I was possibly identified as a “medical person”. Participants were reassured that their GP had no access to their transcripts and they would not be identifiable but it may still have affected what they told me during the interviews. Developing the interview was occasionally difficult for participants who felt that knee pain was a natural part of the ageing process, or who were unsure about the future. There was also concern on my part not to lead participants to form expectations they did not actually have.

As a psychologist who has spent several years looking at the psychological and physical impact this condition *can* have, there was a danger that I may have been looking for issues or problems that did not actually exist in the analysis. To address this possibility a colleague analysed a sample of the transcripts and agreed with my analysis, and the process involved constant referral to the data to ensure that the emerging themes could be supported. Several participants said that OA was just something they accepted as part of the ageing process and that they would not let it affect their lives. This came as something of a surprise to me as some of the participants had considerable pain and functional difficulties.

CHAPTER 6: DEVELOPMENT OF THE KNEE PAIN BELIEFS

QUESTIONNAIRE (KPBQ)

6.1 INTRODUCTION

This chapter describes the development of a condition specific questionnaire to measure patient expectations, using the findings from the qualitative interviews of chapter 4. Currently, no instruments exist to measure individuals' ideas about their OA in terms of illness expectations and treatment expectations. Measures have been developed that include items on self-efficacy and outcome expectations (perceived consequences of action) in OA (Gecht et al., 1996), but condition-related expectancies have been largely ignored. Various assumptions have been made about the possible roles of risk expectations, for example that they are an initial starting point for motivation (Schwarzer, 1992a), and recent work has begun to examine risk awareness, alongside outcome expectations and self-efficacy in patients with chronic heart disease, producing similar findings to studies in healthy populations (Sniehotta et al., 2005; Schwarzer & Fuchs, 1996) (see section 2.1.5).

Chapter 7 investigates the role of expectations in exercise behaviour. Due to the paucity of measures in this area, the construction of a questionnaire was necessary to quantitatively examine expectations held by individuals with OA, longitudinal changes in these beliefs, and the impact of expectations on activity levels in this condition. The following sections describe the development of the Knee Pain Beliefs Questionnaire (KPBQ), through factor analysis and testing of its reliability and validity.

6.2 KPBQ DEVELOPMENT

6.2.1 Initial Stages of Development

A criticism of many expectations questionnaires is that items are often ad hoc and reflect areas that researchers, rather than respondents, feel are relevant, or are developed from reviews of the existing literature (see section 2.2.3). This may not adequately represent areas that are important to the target group, particularly if little or no previous research exists. Qualitative methodology addresses this problem by gathering individuals' beliefs about a topic and ensuring that items are patient driven.

6.2.1.1 Item Selection

To generate questionnaire items 26 individuals with knee OA participated in semi-structured, one-off interviews. The methodology and findings are detailed in chapter 4. The interviews centred around participants' current expectations about treatment and outcome (beliefs about what will happen with regards to the condition in the future), and their expectations when their knee pain first started.

The main themes to emerge from the interviews regarding expectations were then used to form items for the KPBQ. These themes were:

- Previous expectations of developing OA
- Initial outcome expectations compared to the current situation
- Evaluation of previous treatment, compared to expectations
- Future expectations of outcome
- Impact of the condition on life in the future
- Future expectations for treatment (e.g. surgery, cure)
- General optimism or pessimism for the future condition

At least one item per theme was required, giving an initial total of 7 items. Whilst the aim of the measure was to explore expectations in more depth than existing measures, participants may have been discouraged from completing a long questionnaire and the amount of missing data may have increased. There was also a potential problem of not being able to generate a sufficient number of items; expectations, unlike for example, illness representations or quality of life, is a relatively specific area and so multiple items may create a high level of redundancy.

In the qualitative interviews some themes were raised more frequently than others so this was used to determine the relative number of items given over to each area.

Participants appeared to be most concerned about future outcomes so four items were developed; changes in the condition, changes in function, necessity of walking aids, and clarity of ideas about future outcome. This last item was included as it became apparent in the interviews that several participants had no concrete ideas about the future. Expectations about function were assessed separately from ideas about the knee pain as interview participants spoke about them separately, and it also addresses the problem of measures assessing expectations using only a general question (see section 2.2.3). Treatment expectations are the main focus of most measures, and whilst this was of interest, fewer items were given over to this area than outcome expectations. Two items were included in the measure which concerned the potential for a cure, and the necessity of surgery in the future. In addition one item related to general optimism for the future, and another the potential impact of the condition on the respondent's life.

The main interest of this measure is individuals' current expectations for the future, so the majority of items concerned this. However, some participants spoke at length about whether their expectations had been fulfilled, and some also raised the issue of whether they had expected to develop OA. Four items were therefore included concerning previous expectations. Two items concerned function and overall knee pain, reflecting the structure of the current expectations section; one related to whether treatment expectations were fulfilled, and another on expectations of developing OA.

6.2.1.2 Ordering of Items

To produce a logical order, items were arranged temporally, so that all items relating to previous expectations were grouped together and presented first, followed by items concerning current expectations.

6.2.2 Initial Version of the KPBQ

6.2.2.1 KPBQ Design

The first version of the questionnaire consisted of 12 items, each answered on a five-point Likert scale, ranging from strongly disagree to strongly agree (see appendix 3). The other main questionnaires used in the outcomes study were the WOMAC and the IPQ-R (section 7.2.2), so the design of the KPBQ was based partly on these measures to maintain a degree of consistency. The five tick boxes and the layout, which was well-spaced and clear, came from the WOMAC and the labels, strongly disagree to strongly agree, came from the IPQ-R. It was felt that maintaining consistency in design would facilitate completion by study participants.

A five-point Likert rating scale was used for responses, which has the unique characteristic of all responses ranging along a continuum of ‘agree-disagree’. An uneven number of options were chosen to provide a middle option for participants rather than forcing them to choose between a positive or negative option. A “neither agree nor disagree” option would give an indication of how many participants held no expectations about specific items. Between five and seven options are suggested as an optimum number (Streiner & Norman, 1995), and as the WOMAC and IPQ-R both used five-point scales this also provided a degree of consistency between measures.

A combination of positively and negatively worded statements was used to avoid “yea saying”, or acquiescence bias, whereby patients tick the same box for each statement (Streiner & Norman, 1995). “Knee pain” was used rather than “OA” or “arthritis” because previous experience indicated that some patients may not be aware that they have arthritis, may not know what OA is, or may not remember the diagnosis. It was felt that use of the term “knee pain” would cause less distress or confusion, and respondents could easily interpret the questions with respect to their symptoms.

6.2.2.2 Testing the First Version

Four participants were given the first version of the KPBQ to complete at home and return in a postage paid envelope, to assess patient understanding and identify any potential problems. They were also invited to comment upon it in terms of comprehension, the wording used, ease of completion and whether they found any questions intrusive or inappropriate. These participants (three females and one male, with a mean age of 72.05, range 62-82, *SD* 10.00) were all enrolled in the rehabilitation trial outlined in chapter 8, and were attending for their six month follow-

up visit. There were no missing data and the only comment was that the layout was clear and all of the items were relevant to their condition. The mean time for completion was 11 minutes (range 1-40, S.D. 19.19), although this included one individual who took 40 minutes to complete it; no reasons for this were given by the participant. The other participants took a mean of 2 minutes. Only a small sample completed this version as comments from experts were received during this period, which necessitated changes to the questionnaire.

The KPBQ was given to three experts to review; one health psychologist and two research physiotherapists with expertise in health beliefs and knee pain. They were asked to comment on item content, layout, wording and overall coherence. Several alterations to the wording were suggested, particularly for items that asked about previous expectations (from time of onset or diagnosis). The statement “I expected to get better treatment for my knee pain” was felt to be ambiguous as it could have referred to more effective treatment, or better care from health professionals. As a result this item was divided into two new statements: “I was pleased with the treatment I received for my knee pain” and “the treatment I received for my knee pain was worse than I expected it to be”. Item 1 was expanded from “I expected to get knee pain as I got older” to “before I had knee pain I expected to develop it when I got older”, and was moved from the section on expectations at onset of knee pain, as this item was concerned with beliefs *before* onset of the condition. The word “now” was added to items 2 and 4 to emphasise the time period the statements were referring to. Item 10, “I have no idea what will happen in the future with my knee pain”, was removed as it could not be rated as a positive or negative expectation – it related to a presence, or

lack, of a belief. Following these alterations the measure still contained 12 items, and there were no recommendations to include additional items.

6.2.3 Second Version of the KPBQ

The second version (see appendix 3) was given to seven patients attending for their six month follow-up visit (4 females, mean age 66, range 55-74 (*SD* 8.12)). These individuals were similar to those completing the measure in the outcomes study of chapter 8, they were aged fifty and over, had chronic knee pain, and had not undergone knee replacement surgery. The measure was completed at the main study's primary end point when participants were no longer receiving any treatment that could have had a direct influence on expectations.

Questionnaires were completed at home and participants were given a stamped addressed envelope in which to return them. As before, participants were asked to record the length of time they took to complete the questionnaire, in addition to any comments or suggestions they had. These patients took a mean of 6 minutes (range 2-15 minutes, *SD* 4.96) to complete the questionnaire, and, as with the first version, there were no missing data. Two patients (one male, one female) also read through the measure with the researcher, "thinking out loud", where they described how they formulated their responses, to check that the meaning of each question was clear (Streiner & Norman, 1995). No problems were detected with any of the items.

The second measure was again examined by the physiotherapy researchers and the health psychologist, and also by a rheumatology nurse practitioner and a health services research fellow who both had extensive experience of working in the area of

patient-centred rheumatology. It was recommended that questions concerning evaluation of treatment be clarified to reduce ambiguity, so the statement “I was pleased with the treatment I received for my knee pain” was changed to “I was pleased with the outcome of the treatment”. Item 4 was changed from “the treatment I received was worse...” to “the treatment was not as helpful...”. It was also suggested that the final question be changed from “optimistic” to “hopeful” as some participants may not fully understand the term “optimistic”. However this was not altered as respondents in the pilot studies seemed to have no difficulty with interpretation, and it would have meant using “optimistic” and “hopeful” interchangeably, thereby introducing an affective component into the measure (Frowick et al., 1986). Item 7, which asks about future activities, was changed from “worse in the future” to “more difficult in the future” as it was felt that “worse” could apply to pain levels as well as function, whereas “more difficult” referred more explicitly to levels of functioning.

Three participants commented that the layout was easy to follow. One individual was confused by the asterisks, which denoted reversed scoring items, and these were duly removed. This participant also misread item 8, which was negatively worded and suggested that the word “not” be highlighted in some way. Their suggestion was not acted upon as it may have functioned as a prompt to respondents. Two participants found the questions difficult to answer as they had not considered what would happen in the future. However, this was not considered to be problematic as a neutral option was provided for people who felt that they had no expectations. One individual commented that the statements seemed to be more about state of mind than knee pain, but this did not appear to be a criticism, and reflects the purpose of the measure, i.e. examining people’s ideas about their health.

After the alterations were made the measure was again shown to the health psychologist and the physiotherapists who were satisfied with the revised version. It was then administered to a larger sample of patients to enable factor analysis to be conducted, internal reliability and convergent validity to be calculated, and to generate test-retest data (see sections 6.3 and 6.4).

6.3 FACTOR ANALYSIS

Factor analysis is used to “identify a relatively small number of factors that can be used to represent relationships among sets of ...uncorrelated variables” (Norusis, 1993) p.47). It is also used to reduce a large number of variables to a smaller set, which is useful when using multiple regression as it reduces the sample size required. The following section describes the factor analysis of the KPBQ.

6.3.1 Procedure

6.3.1.1 Sample Size

There has been much debate about appropriate sample sizes in factor analysis, and whether absolute numbers or a ratio of participants to variables should be used (MacCallum et al., 1999). For absolute numbers, guidelines for minimum samples range from 100 (Gorusch 1983, as cited in MacCallum et al., 1999) to 250 (Cattell 1978, as cited in (MacCallum et al., 1999). Recommendations for participant to variable ratios vary from 3-6 participants per variable (Cattell 1978, as cited in MacCallum et al., 1999) to 10 and over (Everitt 1975, as cited in MacCallum et al., 1999). Communalities (the amount of variance explained by the components for each variable) are an important determinant of sample size for factor analysis; solutions

with low communalities, or a wide range, require larger sample sizes, so a sample size of 100 is required in studies where all communalities are above 0.6, and between 100-200 is recommended when the communalities are all around 0.5 (MacCallum et al., 1999).

Data for 124 participants (80 baseline questionnaires from the outcomes study and 44 baseline questionnaires from the test-retest data, see section 6.4.2) were entered into a Statistical Package for Social Scientists (SPSS) database (version 11.0). Due to missing items, 112 cases were included in the analysis, a ratio of 9.3 participants to each variable. When the data were run with missing items replaced by the mean, the factor structure did not change, although variable loadings onto components differed slightly. The communalities ranged from 0.43 to 0.77. The participant to variable ratio and communalities scores indicate an adequate sample size.

6.3.1.2 Tests for Normal Distribution

Kolmogorov-Smirnov values were examined, and low significance values were produced for each variable, indicating that data were not normally distributed.

However, this may have been due to a relatively large sample size; in large samples even small differences can result in statistically significant values, even if they are of no practical importance (Norusis, 2004). Normal Q-Q plots, which show the observed values for the variables on the x axis and the corresponding predicted values from a standardised distribution on the y axis, were calculated (Norusis, 2004). Points were sufficiently close to the straight line for all 12 items, indicating a normal distribution.

6.3.1.3 Sampling Adequacy

To ensure that the variables were linearly related to each other, and the sample was therefore suitable for factor analysis, Kaiser-Meyer Olkin (KMO) statistics were examined. The KMO is a value of sampling adequacy, and compares the magnitude of observed correlation coefficients to the magnitudes of partial correlation coefficients (Norusis, 1993). KMO values were classified by Kaiser as: <0.5 – unacceptable; 0.5 – miserable; 0.6 – mediocre; 0.7 – middling; 0.8 – meritorious; 0.9 – marvellous (Kaiser, 1974). The KMO statistic for this sample was .73, indicating reasonable sampling adequacy. In addition, the anti-image correlation matrix, which provides the KMO statistics for each variable, showed all items to be above 0.5 (the lowest value was 0.59), again indicating sampling adequacy.

6.3.2 Findings

6.3.2.1 Factor Extraction

The purpose of factor extraction is to identify underlying constructs that can account for relationships between the variables. Two methods can be used; principal component analysis (PCA) and exploratory factor analysis. These are essentially the same in that they aim to reduce the data, but PCA simply transforms correlated variables into a smaller set of uncorrelated variables which explain the maximum amount of variance in the original data (i.e. restructures the variables). Factor analysis is more ambitious as it postulates a particular model to explain correlations between observed variables (Everitt, 1999).

Both PCA and maximum-likelihood analysis were applied to these data. Maximum-likelihood analysis is a form of exploratory factor analysis which assumes that the data have a multivariate normal distribution. Running both types of analysis allows the researcher to decide which method provides the “best” solution, and to choose accordingly. PCA explained 65% of the total variance compared to 50% explained by maximum-likelihood, which always explains a lower percentage of variance because it attempts to explain covariances between the observed variables and *only* the variance shared between common factors (Everitt, 1999). The communalities for both methods were also examined. The communalities in PCA and maximum-likelihood also differ, because in maximum-likelihood analysis the unique and error variance are removed leaving only the variance a variable shares with the factors (Tabachnick & Fidell, 2001). PCA was chosen as the most suitable method, as its unrotated component matrix had a more logical structure.

During factor extraction, the number of components that best describe the data must be decided upon. The criteria for this are generally arbitrary, but three have been suggested (Everitt, 1999);

1. Acceptance of eigenvalues over 1.00
2. Analysis of a scree plot can indicate where the cut off point occurs – an “elbow” in the plot indicates an appropriate number of components
3. A reasonable solution is suggested if at least 60% of the variance is accounted for.

Four factors had eigenvalues over 1, an “elbow” occurred in the scree plot after four factors and four factors accounted for 65% of variance (see appendix 4). Components 1 and 2 explained 46.5% of the variance, with factor 1 accounting for 32%. Whilst a

two factor solution may be appropriate, components 3 and 4 contributed an additional 18%, and both had eigenvalues over 1.00 (the eigenvalue for factor 5 was only 0.86). After taking the above criteria into consideration a four factor solution was accepted.

6.3.2.2 Factor Rotation

When factors are extracted the component matrix is presented as an unrotated solution, which can be difficult to interpret due to correlations between the factors. Rotation aims to produce a simple structure and increase the interpretability of the solution. Two classes of rotation, orthogonal and oblique, can be used. In orthogonal rotation the axes are maintained at right angles and the loadings onto the factors are exaggerated, increasing large loadings and minimising small ones to produce a set of uncorrelated factors. With oblique rotation the axes are not maintained at right angles and correlations between factors are permitted. This may not produce as clear a structure as orthogonal rotation, but the solution may be more meaningful as it allows correlations between factors (Norusis, 2003).

As with factor extraction, the decision regarding which method of rotation to use is taken by the researcher, based upon which method produces the clearest or most logical solution. For this sample, both varimax (orthogonal) and oblimin (oblique) rotations were conducted, and the varimax algorithm was selected as it produced the most meaningful solution.

Using orthogonal rotation the 4 factor solution in table 6.1 was produced. After examining the variables in each component, the factors were labelled; future state (factor 1), current beliefs (factor 2), defensive optimism (factor 3), and perceived

invulnerability (factor 4). Whilst item 10 had a higher loading on factor 4 than factor 1, the difference was small, and upon inspection it had a better fit with the factor that concerned future state than prior beliefs. Therefore, item 10 was placed in factor 1.

This meant that two factors, future state and current beliefs, accounted for nine of the items, with two more loading onto the optimism factor and 1 item left on its own.

Apart from item 10, all items clearly loaded onto one component only, making interpretation of the solution much simpler.

On the whole, the factor loadings were meaningful, with the items concerning prior expectations and future expectations forming separate factors. Interestingly, two items about the future formed a distinct, separate factor, which was labelled defensive optimism. These items were phrased in a positive way, unlike those in factor 1, which may be why they loaded onto a separate component, but they also appeared to represent a more general view about the future rather than asking specifically at pain, surgery etc, as on factor 1. Item 1, the only item on the KPBQ which looked specifically at participant expectations before the onset of knee pain, loaded onto a factor on its own.

Table 6.1 The rotated component matrix

Item	Component			
	Future state	Current beliefs	Defensive optimism	Perceived invulnerability
Q6 My knee pain will get worse in the future	.836	.097	.130	.018
Q7 My knee pain will make activities such as walking & climbing stairs more difficult in the future	.832	.274	-.014	-.014
Q9 I will need to use walking aids (e.g. walking sticks, wheelchair) in the future	.753	.080	.102	-.051
Q11 I expect to need surgery on my knees in the future	.551	.298	.227	.410
Q10 There is no cure for my knee pain	.491	-.188	.107	-.621
Q3 I was pleased with the treatment I received for my knee pain	.102	.826	.074	.042
Q4 The treatment I received for my knee pain was not as helpful as I thought it would be	-.001	.791	.185	-.014
Q5 My ability to walk and climb stairs now is better than I thought it would be	.333	.688	.216	-.011
Q2 My knee pain now is worse than I thought it would be	.163	.617	.008	-.141
Q12 I am optimistic about the future with regards to my knee pain	.068	.167	.827	.094
Q8 My knee pain will not have a serious impact on my life in the future	.149	.114	.746	-.165
Q1 Before I had knee pain I expected I would develop it as I got older	.158	-.332	-.048	.692

Bold numbers denote factor loadings for each item

6.4 RELIABILITY ANALYSES

A good scale should show good reliability i.e. the responses should be consistent and reproducible. The following section looks at two types of reliability; the internal consistency of the expectations measure, and its test-retest reliability.

6.4.1 Internal Reliability

The internal reliability of a measure is the extent to which items that supposedly measure the same construct correlate with each other. In classical test theory, the sum of the true score (the value for the underlying construct being measured) and the error score is the response to a particular item (Norusis, 2003). A good scale contains a large amount of the true score and only a small amount of error score (Norusis, 2003).

The split-half correlation coefficient method calculates reliability and involves dividing the scale in half and comparing the reliability scores for each part, so in an internally reliable measure the two halves would be highly correlated. The most commonly used measure of internal consistency is Cronbach's Alpha, which is the average of all possible split-half coefficients for a given test (Cronbach, 1951). This method takes into account all the inter-associations between items in the scale and does not depend on how the scale is split (Loewenthal, 2001).

A minimum of two items is necessary for calculating alpha values, although increasing the number of items increases the reliability coefficient (Norusis, 1993). Cronbach's alpha for the whole scale (12 items) was .74, a satisfactory value as the measure is intended for research rather than clinical applications (Bland & Altman, 1997). The squared multiple correlation (which shows how much of a variable's score can be

accounted for by the other variables) for item 1 was low at .10, and the item deletion score (the alpha for the scale if that item is removed) was .79. These two statistics, and the finding that item 1 was a stand alone factor, indicate that this item should be removed from the scale. However, as this is exploratory work, this factor may prove to be important, so was retained. Only the deletion of one other item, item 10, improved the alpha and only by a small amount, therefore its value in the factor subscale should be considered before it is deleted.

The prior beliefs factor contained only 1 item, so the alpha could not be calculated. Cronbach's alpha values were calculated for future state, current beliefs and optimism factors, which contained five, four, and two items respectively:

Future beliefs – This factor had an alpha of .74, and removing item 10 increased the value to .78. The squared multiple correlation for item 10 was .18 indicating that this item does not measure the same construct as the other four factors and should probably be deleted.

Current beliefs – the alpha was .77, and the only item which increased this value upon its deletion was item 2 (“my knee pain now is worse than I thought it would be”), although only by a value of .01, therefore this item was retained.

Defensive optimism – factor three's alpha was .49. This low value is unsurprising as the factor only contained two items, and increasing the number of items increases the reliability coefficients.

The decision was taken to remove just 1 item, item 10; the alpha for “future beliefs” increased without it, which is unsurprising as, of the 5 items on this factor, it had the lowest loading. It is also closer to an illness perception than a true expectation. Factors 3 and 4 were retained as they may prove to be important factors in what is an exploratory study.

6.4.2 Test-retest Reliability

Test-retest reliability is conducted in order to determine whether similar scores are produced when an individual completes the measure at different time points, in other words to examine the measure’s stability. The interval can range from hours to years, although for most psychological measures it is usually between two and fourteen days (Streiner & Norman, 1995). There may be situations where change occurs even over a relatively short period of time, for example quality of life scores may be influenced by fluctuations in pain or mood.

6.4.2.1 Procedure

The measure described in section 6.2.3 was given to 50 participants in the main study who were attending their six month follow-up assessment. They were asked to take the questionnaire home, complete it and return it in a stamped addressed envelope as soon as possible; five completed it at the hospital following their assessment. The sample size of 50 was chosen because if agreement exists, it should be easily detected in a relatively small sample. Forty four questionnaires were returned. Participants who returned the measure were then sent an identical one three weeks after receipt of the first. This interval was chosen because it was relatively short and these individuals were no longer receiving an intervention, so their beliefs were not expected to change

greatly. It was also unlikely that they would remember their previous responses, and would in effect be completing the questionnaire *de novo*. However, not all follow-up measures were returned immediately and may not have been completed on the same day they were received, so the interval for some participants may have been greater than three weeks. Figure 6.1 shows the number of returned questionnaires at each time point and provides demographic data.

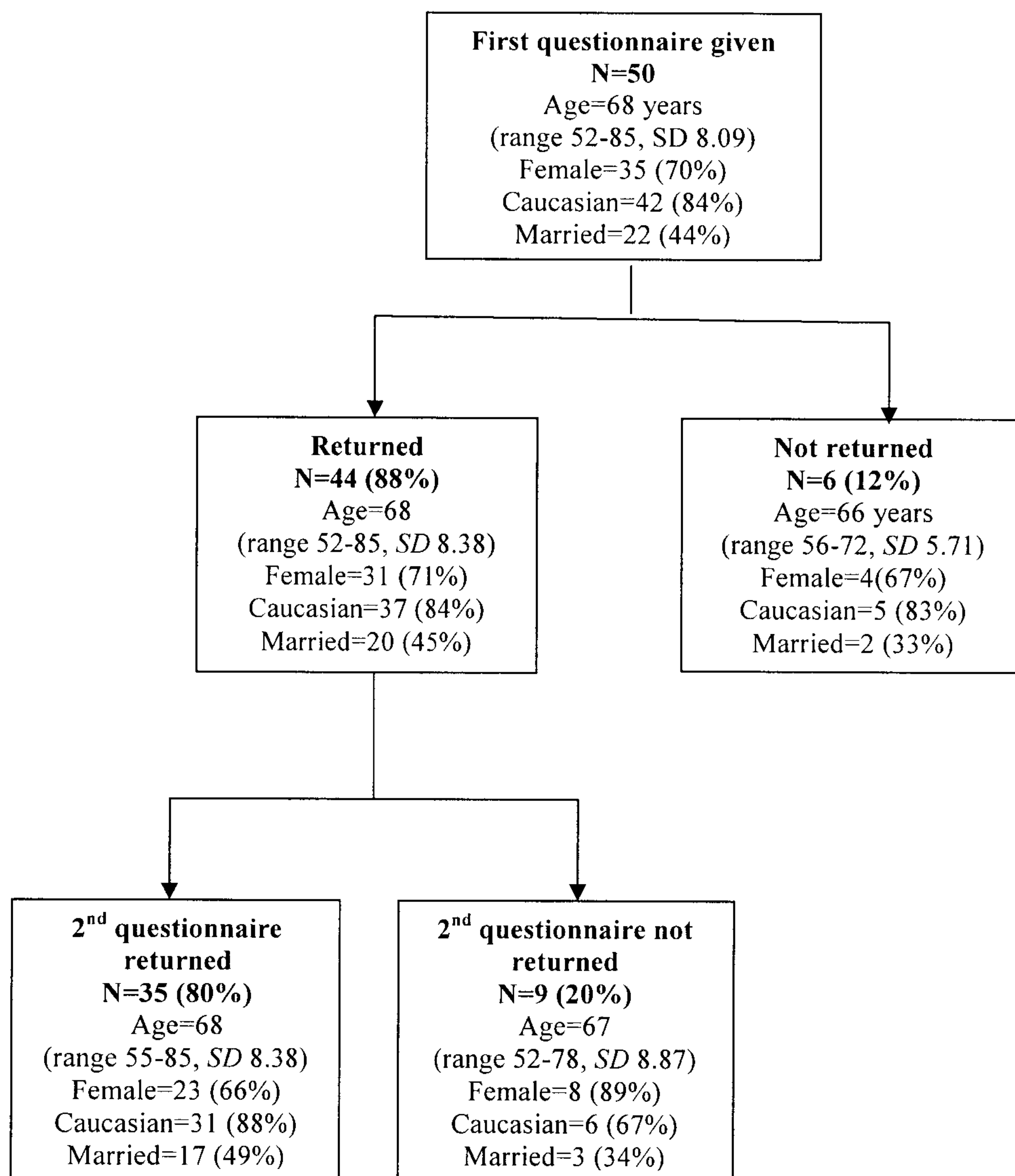


Figure 6.1 Demographic information for returned and non-returned questionnaires

6.4.2.2 Analysis and Results

Scatterplots were generated initially to gain an idea of the degree of association between time 1 and time 2 scores for each of the 4 factors produced in section 6.4.1 (figures 6.2 – 6.5).

Figure 6.2 Factor 1 scatterplot – future state

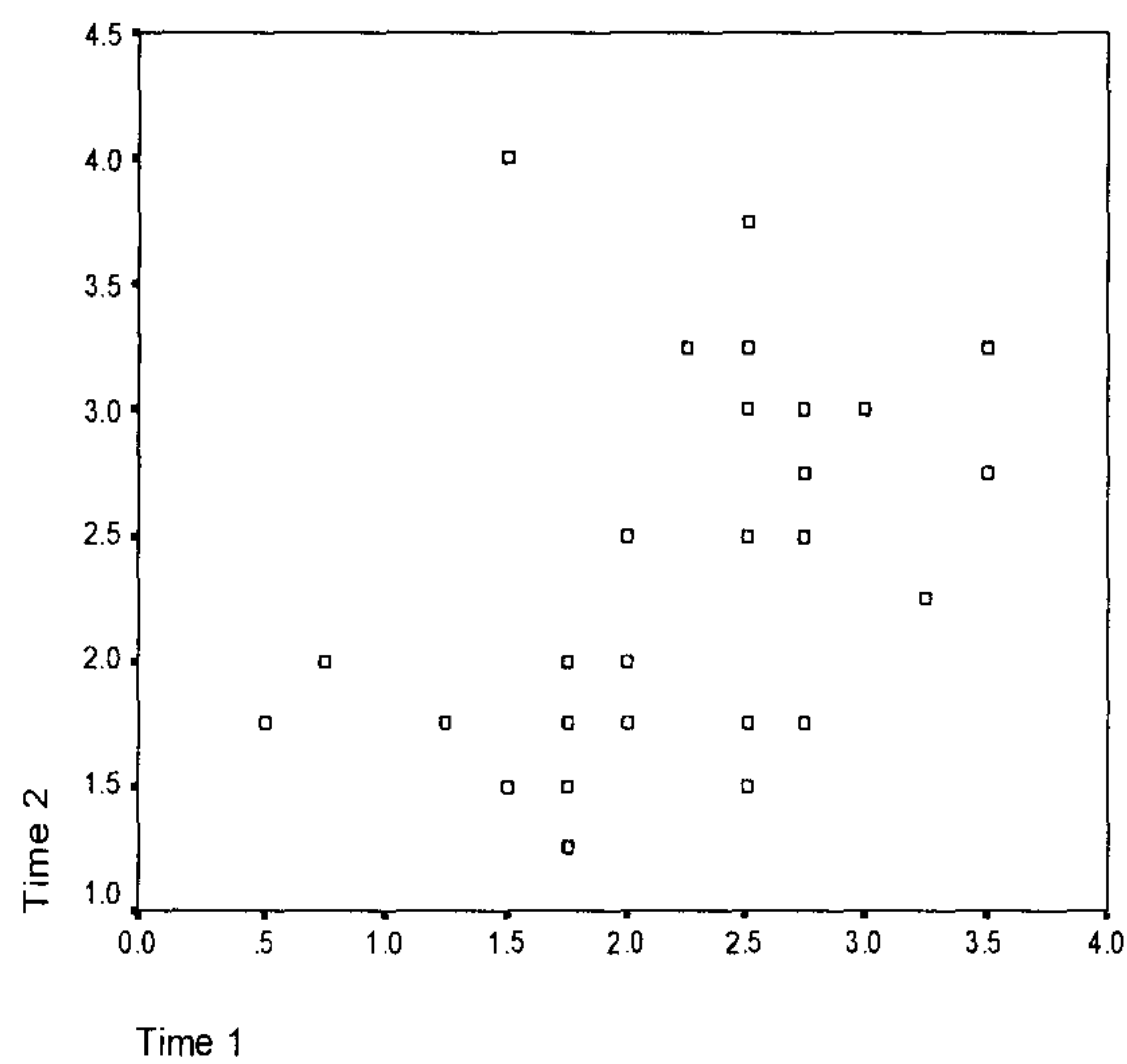
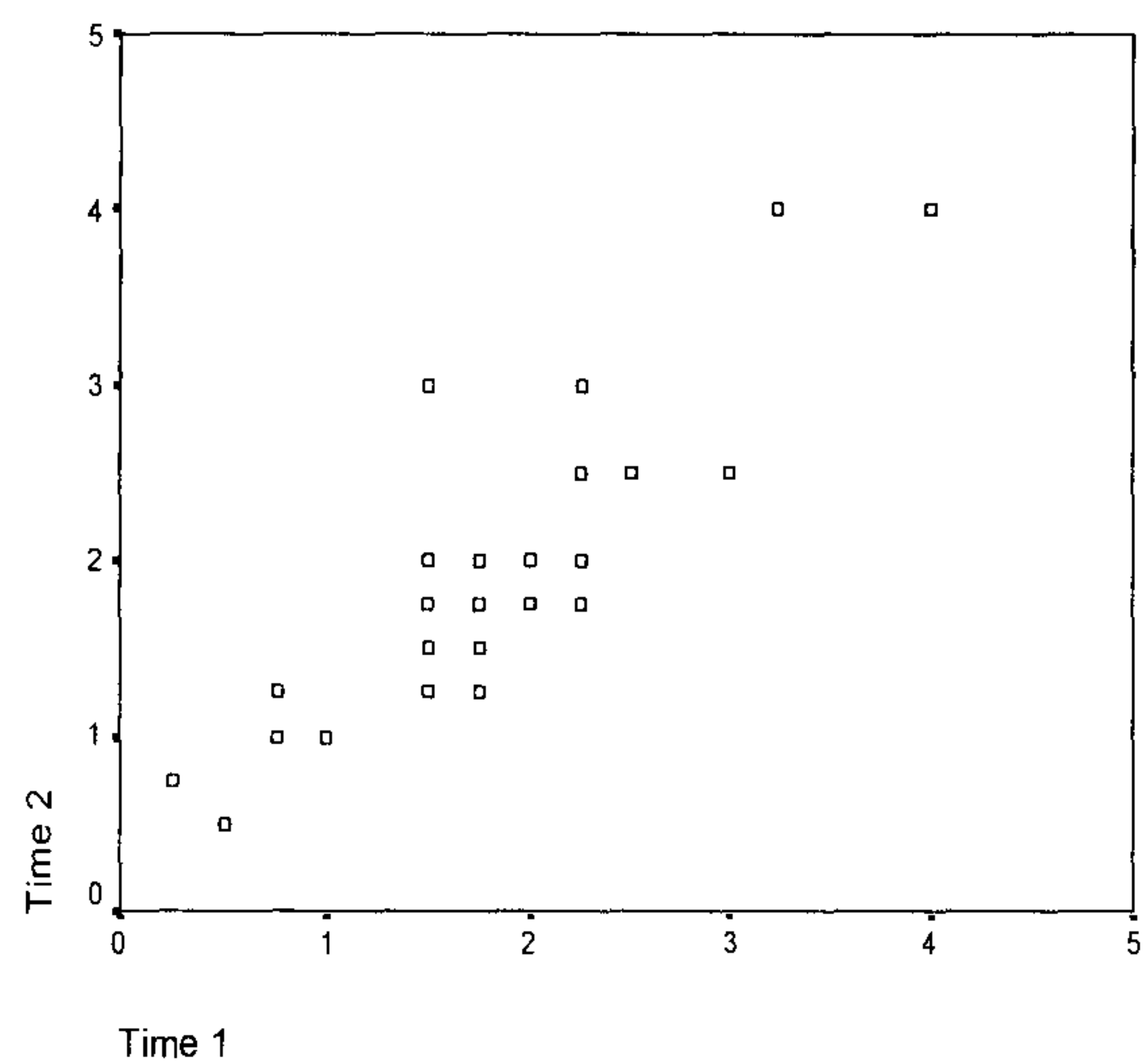


Figure 6.3 Factor 2 scatterplot – current beliefs

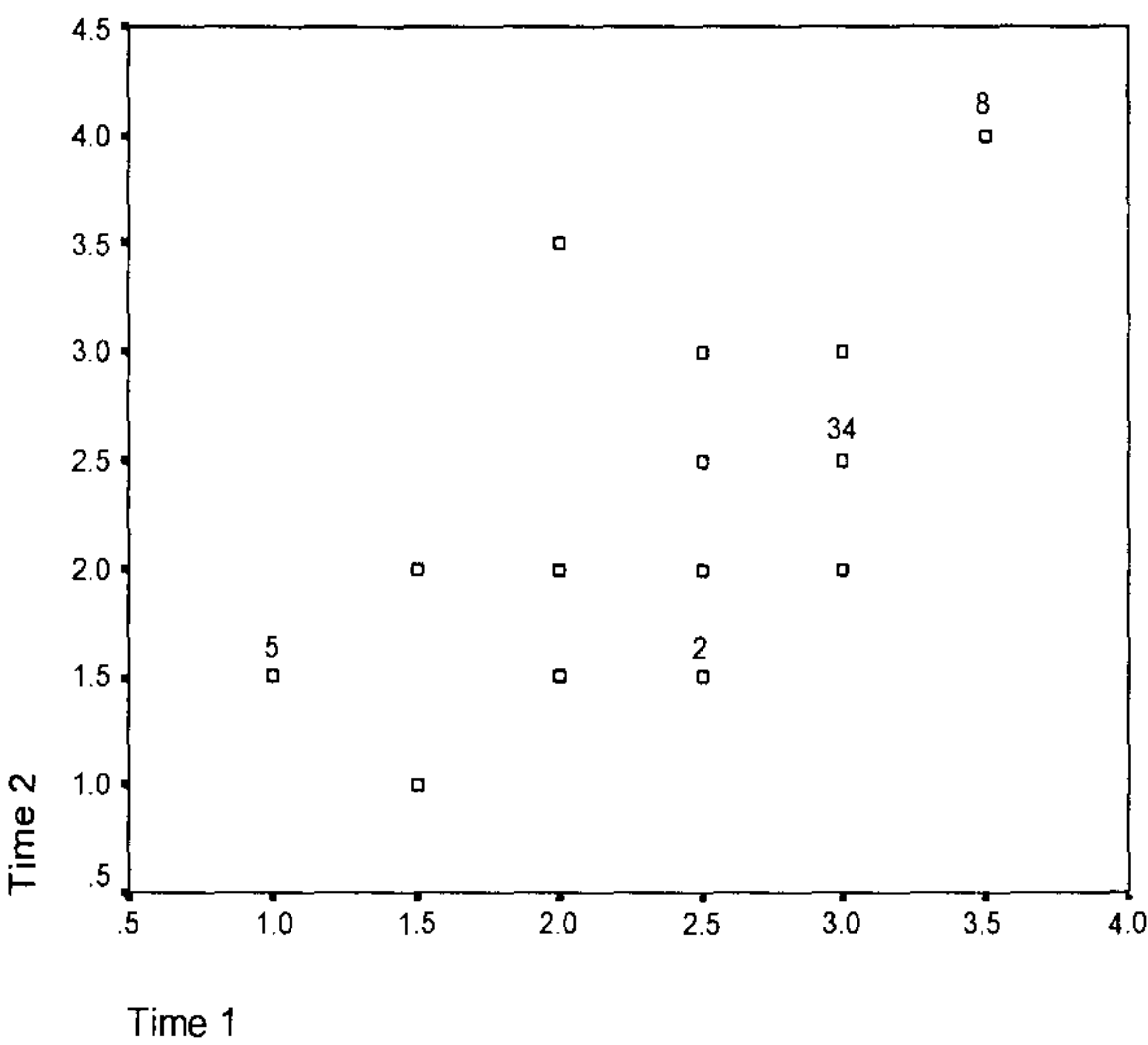
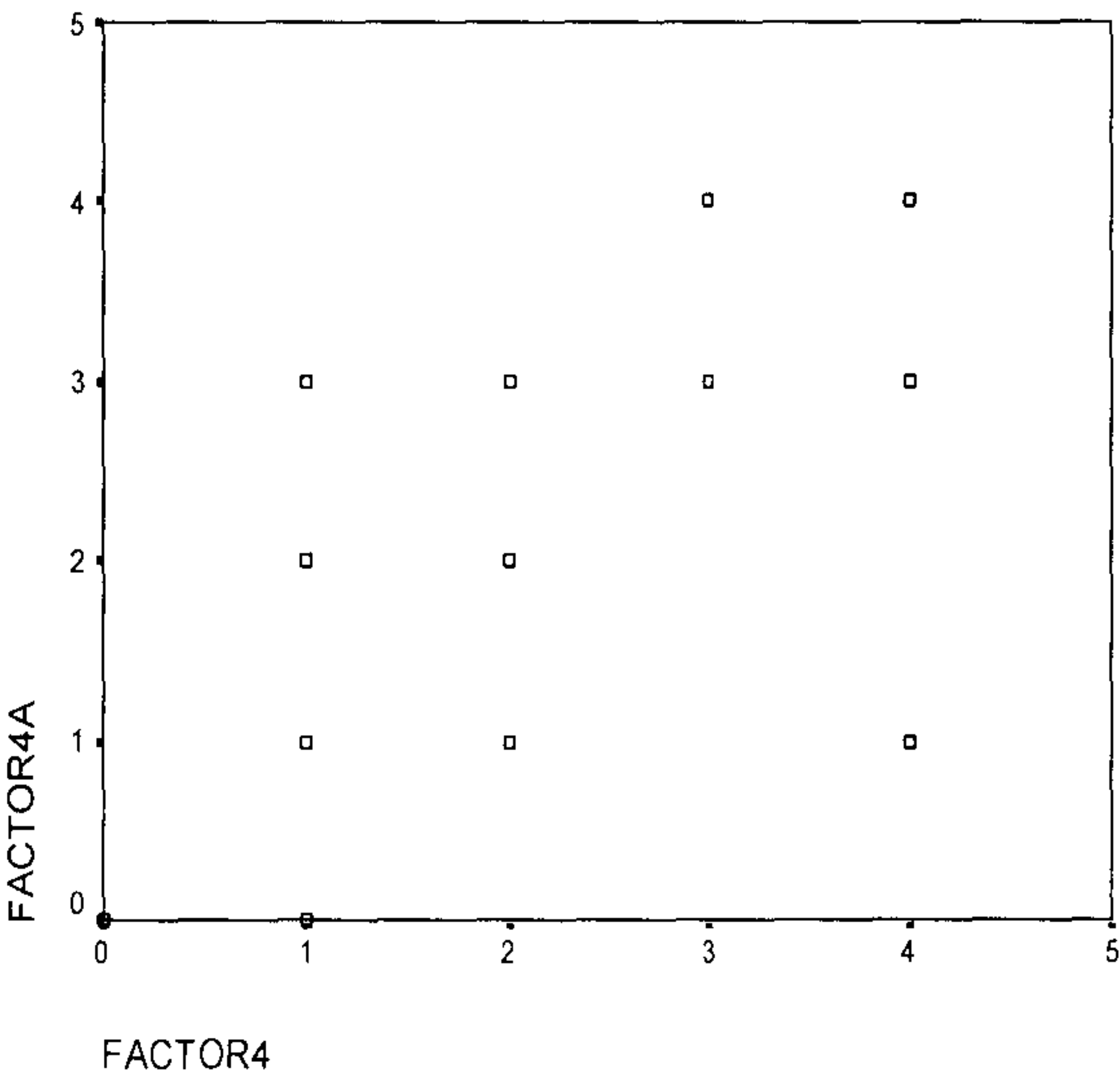


Figure 6.4 Factor 3 scatterplot – defensive optimism

Figure 6.5 Factor 4 scatterplot – perceived invulnerability



The test-retest scatterplot for factor 1 showed the strongest positive correlation, and factor 2 showed a weak positive trend. Positive correlations were shown for factors 3 and 4 but the strength of each was difficult to gauge as multiple cases fell on several points. Pearson’s correlation coefficients were then conducted to indicate the degree of

association between the baseline and follow-up scores for each of the 4 factors produced. These are shown in table 6.2.

Factor	Correlation Coefficient
1	0.86
2	0.46
3	0.61
4	0.72

Table 6.2 Correlation coefficients for test-retest reliability
All values are significant at $p < 0.01$

The correlation scores for factors 1, 3 and 4 were satisfactory, indicating adequate test-retest reliability. However, factor 2 showed lower reliability than desired. The scores for this factor were recoded to explore whether a scale with fewer points (and therefore fewer choices) would improve the reliability scores. The data were transformed to produce three options; negative expectations, positive expectations and neither agree nor disagree. The correlation coefficient was then re-calculated, and only showed a slight improvement, with a value of 0.47, indicating that changing the scale had little influence on test-retest reliability.

A disadvantage of using correlations for test-retest reliability is that because the same measure is used at two time points a degree of correlation would be expected anyway (Bland & Altman, 1986). In addition, whilst a correlation coefficient provides an estimate of association between two variables, it cannot tell us anything about the level of agreement. Rather than assessing the position of points along a normal straight line, a measure of agreement uses the line of equality, and calculates the difference between the points from their mean. Perfect agreement is only achieved if the points lie along the line of equality, whereas a perfect correlation may be achieved if the points lie

along any straight line, and even when poor agreement exists, quite high correlations can be obtained (Bland & Altman, 1986). For example, if the follow-up scores were all 1 point higher, or lower, than the corresponding baseline scores, perfect correlation, but not perfect agreement would exist. Measurement of agreement also takes into account the magnitude of the differences between the two time points, e.g. a difference of 0.5 when a maximum score is 1 is a more serious problem and shows less agreement than a difference of 0.5 when a maximum possible score is 10. Figures 6.6 – 6.9 show the Bland-Altman plots for each factor.

Figure 6.6 Factor 1 Bland-Altman plot – future state

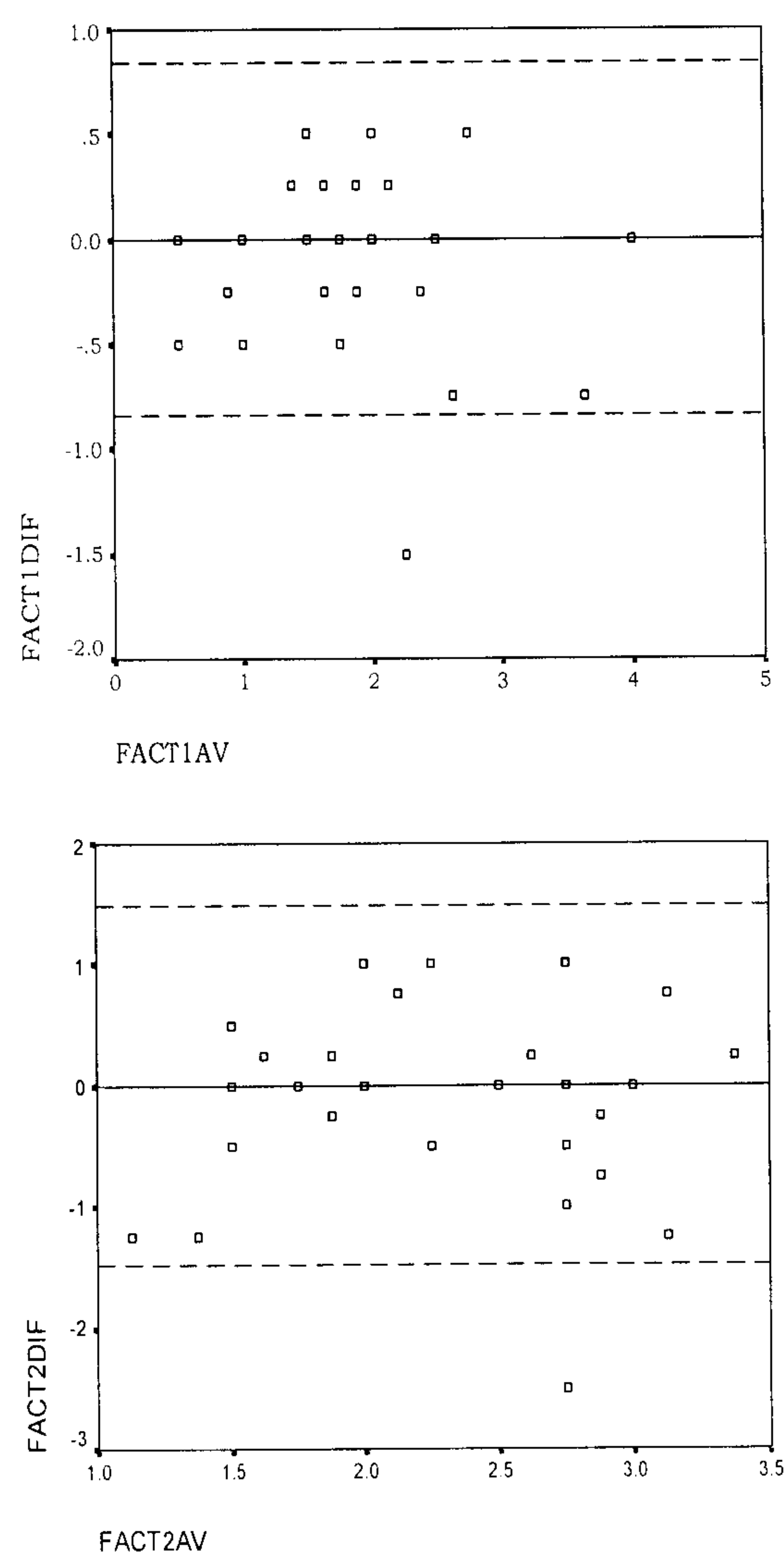


Figure 6.7 Factor 2 Bland-Altman plot – current beliefs

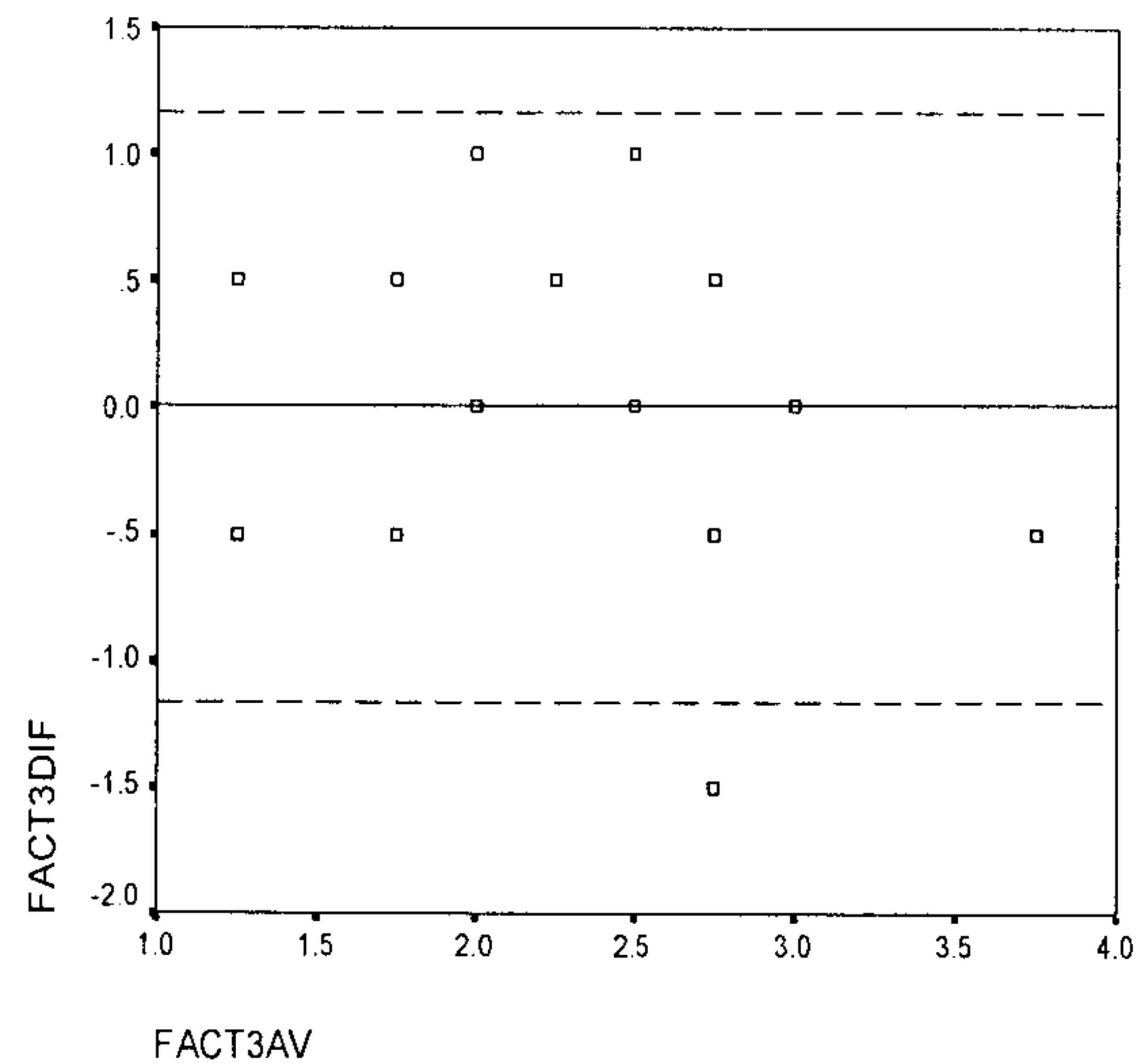


Figure 6.8 Factor 3 Bland-Altman plot – defensive optimism

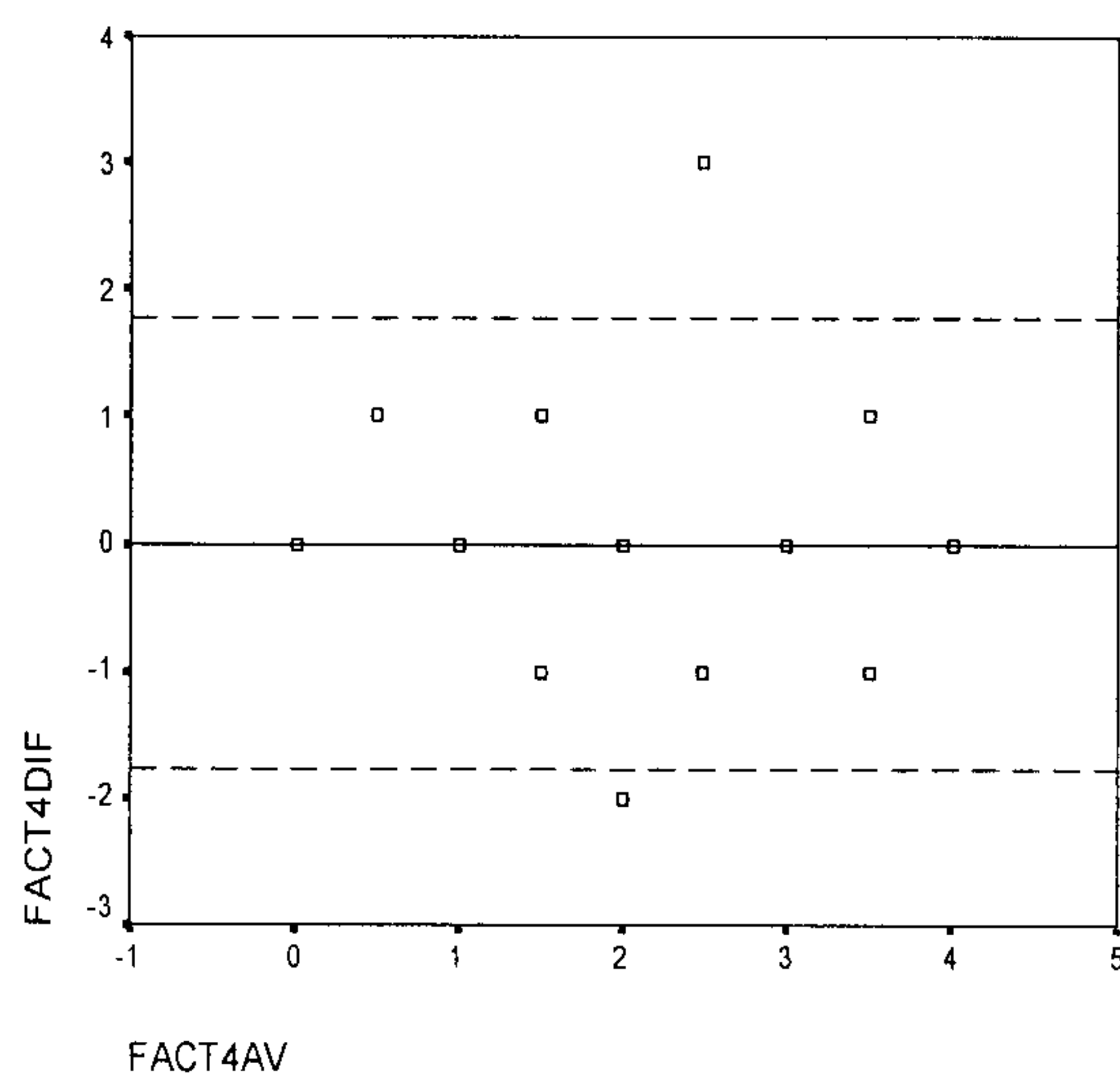


Figure 6.9 Factor 4 Bland-Altman plot – perceived invulnerability

The Bland-Altman plots confirm the correlation coefficients; factor 1 had the smallest standard deviation and the cases clustered most closely around the mean. Although factor 4 has the largest standard deviation, it also has the greatest number of cases falling on the mean (18 out of 35), indicating agreement between the 2 time points.

As a further analysis, cross-tabulation tables were produced, in order to examine how closely time 2 responses corresponded to those from time 1. For factor 1,

unsurprisingly, 11 out of 33 cases corresponded exactly, and in 14 cases the time 2 responses fell either side of the time 1 score, e.g. a mean of 3.25 at baseline and a mean of 3.00 at follow-up. This is in contrast to factor 2, where 11 cases had scores that corresponded exactly, but only 7 out of 33 time 2 scores fell either side of the time 1 score. For factor 3, 14 cases corresponded exactly and 16 fell either side, whilst for factor 4, 18 showed an exact match and 15 fell either side. Because there was only one item in this factor, the range of possible scores was smaller, and the distance between points was greater, i.e. for factor 4, the scores either side of 3 were 2 and 4, compared to factor 1 and 2 where they were 2.75 and 3.25.

6.5 VALIDITY ANALYSES

The concept of validity relates to whether the measure examines the construct under investigation. For example does an expectations questionnaire measure expectations or is it tapping into depression? This is particularly relevant in psychology where considerable overlap between different constructs may occur. Several types of validity exist ranging from basic to complex. This section examines face, content, convergent and discriminant validity. Predictive validity, the ability of the measure to predict a future outcome, is not dealt with in this section as one of the aims of the quantitative study (chapter 7) is to examine whether expectations predict behaviour.

6.5.1 Face and Content Validity

Face validity is a subjective judgement where the measure is examined to check that items are appropriate and logical, there are no omissions, or no items have been included unnecessarily. Because it is a very crude measure, it should only be used in conjunction with other types of validity. Content validity is a more sophisticated form

of face validity, with the assumption that the measure is comprised of a representative sample of the beliefs under assessment. The higher the content validity, the more inferences can be drawn across a variety of conditions. Content validity can be achieved by asking experts in an area to look at a measure and give their opinion on it. ‘Experts’ can include patients, for example, individuals with arthritis can be considered experts of their condition.

In this study, face and content validity were assessed by asking for comments and suggestions from participants who completed the measure, and from researchers and healthcare professionals in this area. In addition, the items were derived from interviews with individuals who were representative of participants completing the KPBQ, which increases the content validity. Sections 6.2 and 6.3 describe the assessment of face and content validity, the findings, and how the measure was altered following suggestions from these experts.

6.5.2 Convergent Validity

In convergent validity the performance of participants on the new test are assessed by correlating their scores against those on an existing measure (ideally the gold standard). This gives an indication of how well the new measure assesses the area under investigation, so the comparison measure should be chosen carefully.

Correlations of between 0.4 and 0.8 are desirable; anything above suggests the two measures are highly correlated and calls into question the necessity of developing an alternative measure (Streiner & Norman, 1995).

The lack of available measures assessing expectations, and dissatisfaction with existing ones, necessitated the development of the KPBQ. Therefore, the identification of a suitable questionnaire to assess convergent validity was problematic. Because of these issues, the revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al., 2002) was chosen as the standard (see section 7.2.2 for more on this measure). It is a widely used, well validated measure that includes items on expectations. The data are from the baseline sample of 80 participants from the study in chapter 8; the IPQ-R and KPBQ were completed at the same time. A small number of items from the total of 40 IPQ-R beliefs were identified as being relevant to some of those on the KPBQ, but not all the KPBQ items could be matched with those on the IPQ-R, because there were no equivalent items.

Table 6.3 shows the correlations between selected KPBQ items and equivalent items from the IPQ-R. Only 4 coefficients were in the desired range of 0.4 to 0.8, and they fell at the lower end. It was surprising that item 12 did not correlate higher with items 18 and 19 on the IPQ-R (a negative correlation would have been expected between 12 and 19), although it is possible to be optimistic without expecting an improvement in their condition, or perhaps respondents were answering item 12 in terms of a general disposition rather than specifically about their knee pain. The correlation between items 5 and 10a was also lower than expected, possibly because item 5 asked about comparing previous expectations with the current situation, whilst item 10 asked respondents to compare their current and previous functioning.

KPBQ items	IPQ-R items	Correlation Coefficients
“My ability to walk & climb stairs now is better than I expected it to be” (5)	“My knee pain has major consequences on my life” (7)	-.44*
	“My knee pain means I cannot walk & get about as much as I used to” (10a)	-.30*
“My knee pain will get worse in the future” (6)	“My knee pain will improve in time” (18)	-.48*
	“My knee pain is likely to be permanent rather than temporary” (2)	.42*
“My knee pain will make activities such as walking & climbing stairs more difficult in the future” (7)	“My knee pain will improve in time” (18)	-.47*
“I am optimistic about the future with regards to my knee pain” (12)	“My knee pain will improve in time” (18)	.10
	“There is very little that can be done to improve my knee pain” (19)	.04

Table 6.3 Convergent validity of KPBQ

*Significant at .01 level (Numbers in brackets correspond to items on the questionnaires)

6.5.3 Discriminant Validity

The use of the IPQ-R also allowed discriminant validity to be assessed. This is the opposite of convergent validity; items are chosen which are hypothesised to be dissimilar and unrelated to the measure being tested and are therefore *not* expected to correlate (correlations should be as close to zero as possible). Because the IPQ-R asks about current beliefs as well as expectations, more items were suitable for discriminant analysis than for convergent validity. Table 6.4 shows the correlation coefficients for each item on the KPBQ.

Compared to the convergent analyses, discriminant validity was much more satisfactory; all of the planned correlations were low and non-significant, indicating

that the KPBQ items were not measuring, for example, emotional representations or illness coherence.

Table 6.4 Discriminant Validity of KPBQ

KPBQ items	IPQ-R items	Correlation Coefficients
“Before I had knee pain, I expected I would develop it as I got older” (1)	“I go through cycles in which my knee pain gets better and worse” (32)	.00
“My knee pain now is worse than I thought it would be” (2)	“The negative effects of my knee pain can be prevented (avoided) by my treatment” (21)	-.03
“I was pleased with the outcome of the treatment...” (3)	“My knee pain is a mystery to me” (25)	.00
“The treatment I received for my knee pain was not as helpful as I thought it would be” (4)	“The course of my knee pain depends on me” (14)	-.01
“My ability to walk & climb stairs now is better than I expected it to be” (5)	“My knee pain comes and goes in cycles” (30)	.10
“My knee pain will get worse in the future” (6)	“My knee pain has serious financial consequences” (10)	.01
“My knee pain will make activities such as walking & climbing stairs more difficult in the future” (7)	“I don’t understand my knee pain” (26)	.11
“My knee pain will not have a serious impact on my life in the future” (8)	“My knee pain strongly affects the way others see me” (9)	-.08
“I will need to use walking aids in the future” (9)	“I have a clear picture or understanding of my knee pain” (28)	.12
“I expect to need surgery on my knees in the future” (11)	“The symptoms of my knee pain puzzle me” (24)	.07
“I am optimistic about the future with regards to my knee pain” (12)	“My knee pain strongly affects the way others see me” (9)	-.04

All correlations $p > .05$

6.6 FINAL VERSION

This chapter has described the development of the Knee Pain Beliefs Questionnaire (KPBQ), an 11-item, patient derived, self-report measure, to assess expectations in individuals with knee pain. Following factor analysis 4 factors were produced; future state, current beliefs, defensive optimism and perceived invulnerability, which reflected the initial structure of the questionnaire. Three of the factors (future states,

defensive optimism and perceived invulnerability) showed acceptable test-retest reliability, whilst future state and current beliefs had good internal reliability. The current beliefs factor showed poor test-retest reliability, and a wide spread of agreement in the cross-tabulations. Possible reasons for these findings should be investigated in future work. One problem with attempting to assess test-retest reliability is that little work has previously been conducted on the stability of expectations, so what constitutes ‘good’ test-retest reliability is unclear. Test-retest reliability for current beliefs was low, which may be expected as day-to-day fluctuations in symptoms may be reflected in participants’ responses.

Discriminant validity of the items was good, however, convergent validity was lower than desired, which may have been due to the use of the IPQ-R as the comparison measure; the questionnaires may not have been similar enough to properly assess convergent validity. However, a lack of satisfactory measures of expectations (the reason for developing the KPBQ) meant that the IPQ-R was the most appropriate instrument to use.

The following chapter describes the application of the KPBQ in an intervention for individuals with knee pain, which includes testing the measure’s predictive validity.

CHAPTER 7: A LONGITUDINAL STUDY EXAMINING THE ROLE OF EXPECTATIONS ON EXERCISE BEHAVIOUR IN KNEE OA

7.1 INTRODUCTION

7.1.1 Background

The previous chapter described the development of the Knee Pain Beliefs Questionnaire (KPBQ) to measure individuals' beliefs about their knee pain. Factor analysis identified four factors (future state, current beliefs, defensive optimism, and perceived invulnerability). This chapter tests the questionnaire in a convenience sample of knee pain patients participating in a trial of physiotherapy, to examine longitudinally the impact of these beliefs on activity behaviour, and their stability over time.

To date, there has been a lack of studies examining the different influences of self-efficacy, outcome and illness expectations. Those that exist have found that self-efficacy and outcome expectations explain greater amounts of variance in intentions and behaviour in relation to healthy eating and testicular self-examination in healthy populations (Schwarzer & Fuchs, 1996; Barling & Lehmann, 1999) and exercise intentions in cardiac patients (Sniehotta et al., 2005) than illness (or risk) expectancies. This may be due to how expectations about a condition are measured; the numbers of items are usually small and not patient derived. In addition expectations are often only measured at baseline, so little is known about the extent to which they can change. As an example it is unclear whether an intervention that provides self-management information can alter these illness expectations.

Knowing how malleable expectations are would provide insight into the mechanisms by which they may change and indicate whether they can be modified through an intervention. It is also possible that a subsequent change in behaviour, such as increased exercise levels, would in turn alter expectations. Studies in this area have tended to examine unidirectional relationships, i.e. the influence of expectations on behaviour or other outcomes, such as the one shown in figure 7.1a, but do not look at circular interactions, such as that shown in figure 7.1b.

Figure 7.1a Simple relationship between expectations and outcome

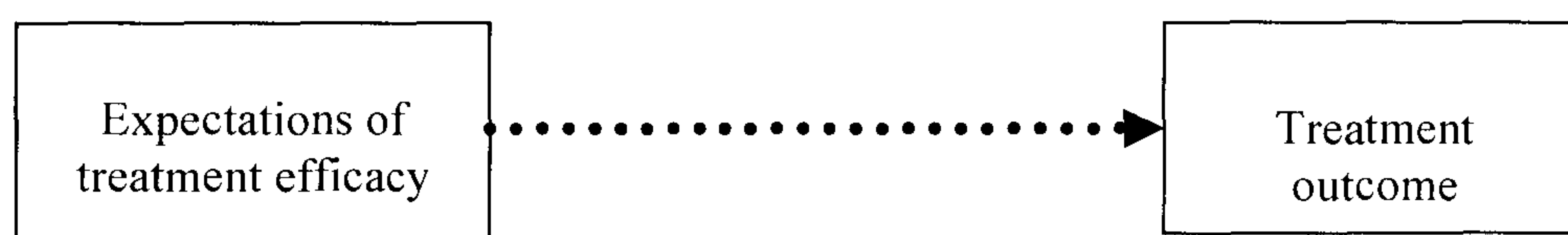
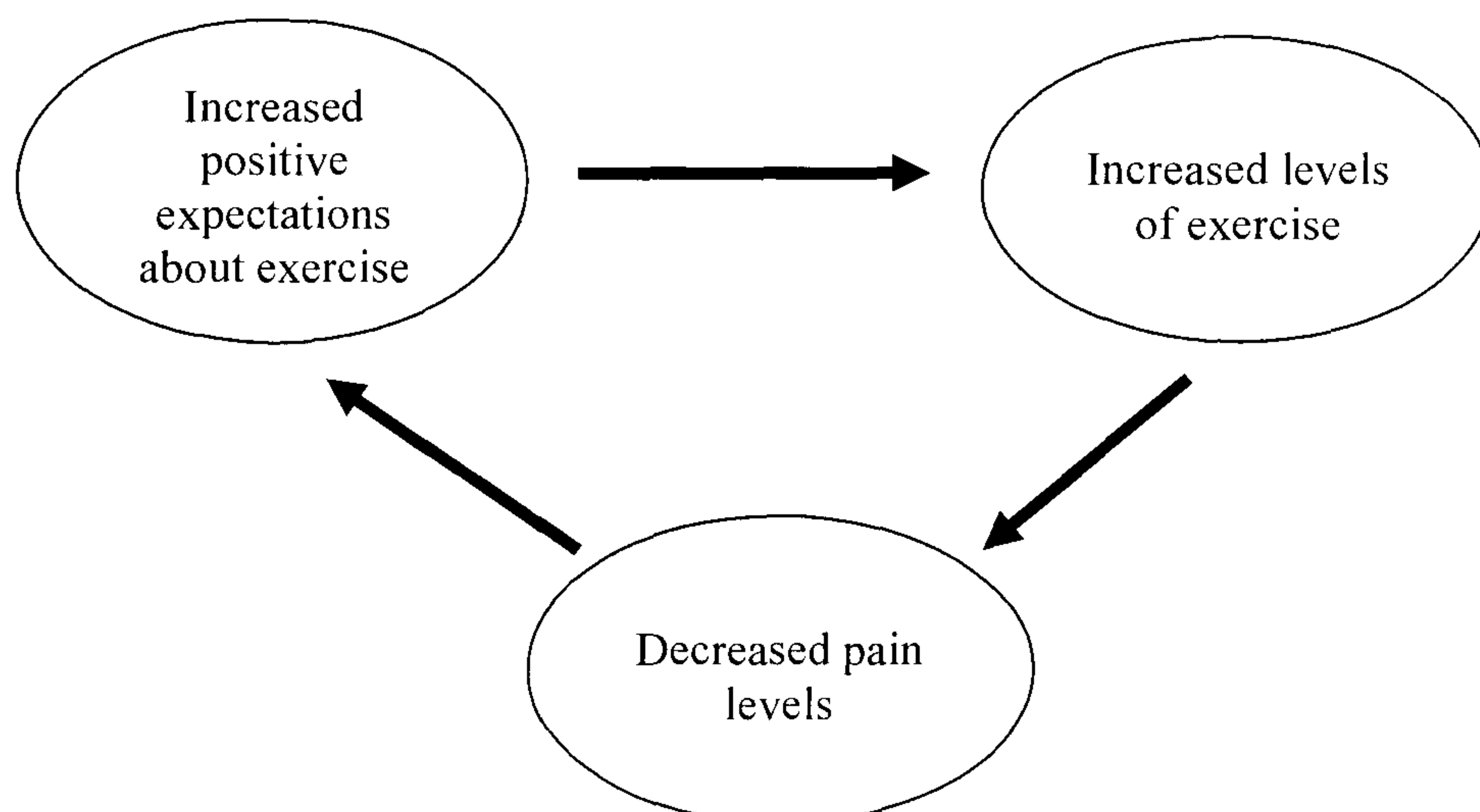


Figure 7.1b Possible circular relationship between expectations and outcomes



Little work has been conducted on the different types of expectations, so this chapter examines whether specific beliefs about knee pain have different effects on behaviour, and how stable specific and more general optimistic beliefs about the condition are.

Previous work suggests that being overly optimistic may be detrimental as individuals believe they are not at risk from the problems related to the condition, and this will be investigated in this chapter (Davidson & Prkachin, 1997).

7.1.2 Study Aims

Greater understanding of how expectations change, and the relationship between expectations and behaviour could enable the development of more effective interventions. The study described in this chapter aimed to answer the following questions:

- Are expectations of illness, self-efficacy, and outcome expectations related to exercise behaviour?
- Are illness expectations **alone** related to exercise behaviour?
- How stable are expectations over time?
- How much variance in self-reported activity do expectations variables account for longitudinally?

7.1.3 Study Hypotheses

The following hypotheses were investigated:

General Primary Hypothesis:

1. Baseline illness expectations will be significantly related to levels of baseline self-reported activity.

Specifically:

1a. Participants with more positive baseline expectations and current perceptions of their condition will have higher self-reported activity.

- 1b. Participants with higher self-reported defensive optimism and perceived invulnerability (i.e. did **not** expect to develop knee pain) will have lower self-reported activity.
- 1c. Participants with higher self-efficacy and higher expectations of exercise outcome will have higher self-reported activity.
- 1d. Illness expectations will contribute significantly to the prediction of activity levels, after controlling for outcome and self-efficacy expectations.

Secondary Hypotheses:

- 2. Baseline illness expectations and other KPBQ variables will account for significant amounts of variance in activity levels at time 2 and time 3.
- 3. Illness expectations and current beliefs will differ significantly across timepoints, whilst defensive optimism and perceived invulnerability will not change.

7.2 METHODS

7.2.1 Participants

A total of 90 consecutive patients with knee pain were recruited over an eleven month period. All were participating in a clinical rehabilitation trial (Hurley et al, 2007), which randomised knee pain patients to 1 of 3 arms (individual rehabilitation, group rehabilitation and control) (see 7.2.5 for intervention information). Four patients were not included: two with reading difficulties had no one at home to assist them with the questionnaires; two showed poor levels of understanding and were subsequently withdrawn from the trial.

The 90 participants represent a subsample of the 418 patients recruited into the clinical trial. The inclusion and exclusion criteria for the main trial are shown in table 7.1:

Inclusion Criteria	Exclusion Criteria
Aged fifty and over	Knee replacements, or given a date for surgery
Previous visit to their GP about knee pain	Terminal illness
English speaking	Unstable medical or psychological conditions
Able to attend assessments at the hospital	Type I diabetes
Able to participate in the exercise programme	Severe pain in other joints that would interfere with assessments of knee pain

Table 7.1 Inclusion and exclusion criteria

See section 7.3.1 for analyses on the representativeness of these participants.

7.2.2 Measures

A number of self-report measures were completed by participants, encompassing a range of physical and psychosocial features considered relevant to individuals with knee pain. The KPBQ, described in chapter 6, was developed to measure beliefs about knee pain, and an activity measure was also developed to assess the type, duration and frequency of activities performed by participants. Activity measures already exist, but were not suitable for this study for a number of reasons, including not being relevant to retired individuals (Baecke et al., 1982), not asking about the types of activities performed (Godin & Shephard, 1985), and ignoring duration of activity, therefore giving a potentially distorted picture of the amount of activity performed (Mailloux et al., 2006).

Participants completed the following questionnaires (see appendices 3 and 5):

1. *Knee Pain Beliefs Questionnaire (KPBQ)*: This 11-item measure asks specifically about patient expectations of progression of their condition and treatment related to their knee pain and consists of 4 factors; future state, perceptions of current

condition, defensive optimism, perceived invulnerability. Each item is rated on a 5-point Likert scale, ranging from strongly agree to strongly disagree and the measure is scored by summing item scores for each factor and then calculating the mean score. Scores range from 0-4 for all factors, with higher scores indicating more positive beliefs (see appendix 3). From this point on, the future state factor will be referred to as illness expectations to reflect its content and role in the following analyses.

2. *Revised Illness Perceptions Questionnaire (IPQ-R)* (Moss-Morris et al., 2002): a widely used, generic measure with established psychometric properties (Hagger & Orbell, 2003) based on Leventhal's Self-Regulatory Model (Leventhal et al., 1980) and revised from the original IPQ (Weinman et al., 1996), the IPQ-R looks at patients' specific beliefs about the symptoms, causes, management and prognosis of their condition. Responses to statements concerning causes and beliefs are given on a 5-point Likert scale, and a mean score ranging from 1-5 is produced for each of 7 factors; timeline, consequences, personal control, treatment control, illness coherence, cyclical timeline and emotional representations. Symptom beliefs are dichotomously scored then summed to give a total score for identity beliefs. This version of the IPQ-R was adapted to specifically address knee pain, with two extra items added to the consequences section; "my knee pain means I cannot walk and get about as much as I used to" and "my knee pain makes me more dependent on others".
3. *Activity measure*: designed specifically for this study the self-report activity measure asks about the number of different activities (e.g. walking, gardening, bowls) performed in the last month, the frequency and the duration of reported activities. Two academic physiotherapists with a specific interest in exercise for

knee pain verified that the list was comprehensive and appropriate to the population. The number of activities was summed, whilst frequency was obtained by adding together the frequency of activities per week and dividing by seven to give a mean number of activities per day. Total activity was calculated by multiplying the frequency for each activity by the duration, adding together the values for each activity and then dividing by 7 to produce a daily activity total. This was represented in 15 minute activity units so a mean of 4.00 would represent 60 minutes of activity per day.

4. *WOMAC (Western Ontario McMaster University) OA index* (Bellamy et al., 1988): this is an OA specific measure which focuses on the last 48 hours and is divided into 3 sections; pain, stiffness and function. Each item is rated on a 5-point Likert scale from none to extreme. Scores range from 0-20 for pain, 0-8 for stiffness and 0-68 for function, with higher scores indicating greater problems. The subscales can be summed to produce a total score ranging from 0-96. The WOMAC has good psychometric properties (Stucki et al., 1998; Bellamy et al., 1988) and is part of the OMERACT core measures for OA trials.
5. *Hospital Anxiety and Depression Scale (HADS)* (Zigmond & Snaith, 1983): a widely used measure of anxiety and depression levels during the previous week, the HAD contains 7 anxiety and 7 depression items with 4 options for each item. Possible scores range from 0-21 for both anxiety and depression subscales, with scores of eleven or more indicating “caseness” (Zigmond & Snaith, 1983). The HADS has well-established validity and reliability (Herrmann, 1997).
6. *Beliefs about exercise scale* (Gecht et al., 1996): this consists of four sections: self-efficacy, barriers to exercise, benefits of exercise and impact of exercise related to arthritis (i.e. exercise outcome). Level of agreement with each item is indicated on

a 5-point Likert scale from strongly disagree through to strongly agree and items are summed to produce a score for each section, which can be combined to produce a total score. Scores range from 4-20 for self-efficacy, 3-15 for barriers and benefits, 7-35 for impact, and 17-85 for the overall score. This scale has previously been shown to have good to excellent internal consistency for all 4 subscales (Gecht et al., 1996).

7.2.3 Ethics

Ethical approval for the clinical trial was obtained from the Local Research Ethics Committees of King's (Ref No. 99-261), St Thomas' and Guy's (Ref No. EC99/814) and Lewisham (Ref No. 00/04/09) Healthcare Trusts. Chairman's action was obtained from King's College Hospital Research Ethics Committee to collect the additional data on expectations and other beliefs related to knee pain (see appendix 1).

7.2.4 Procedure

Participants were seen at three time points: time 1 – baseline; time 2 – approximately eight weeks after baseline; time 3 – approximately eight months after baseline.

At each of the three assessments participants completed the WOMAC, HADS and beliefs about exercise questionnaires. They were given the KPBQ, IPQ-R and activity scale to complete at home and were provided with a stamped addressed envelope marked with their study number, in which to return them. The questionnaires were administered in this way as, particularly with the baseline visit, assessments were often over an hour long and some participants may have been discouraged from continuing

with the study due to the number of questionnaires. In addition, previous participants in the main study had completed the IPQ-R at home.

For data completed at the time of assessment, no data were missing because questionnaires were checked. For questionnaires completed at home 4% of items were missing from the KBPQ and 10% from the IPQ-R (see section 7.3.4 for information on how missing data were handled). Any participants who had not returned their questionnaires within three weeks were contacted by telephone to remind them to do so and to check there were no problems with completion.

All questionnaire data were entered into an SPSS database (version 11.5) by the author, who was blinded to treatment allocation. Baseline data were entered upon receipt, but time 2 and time 3 envelopes were not opened until the participants had attended their time 3 visit. This avoided the possibility of unblinding occurring if patients had written anything on their questionnaires which could reveal their identity or group allocation.

7.2.5 Trial Intervention

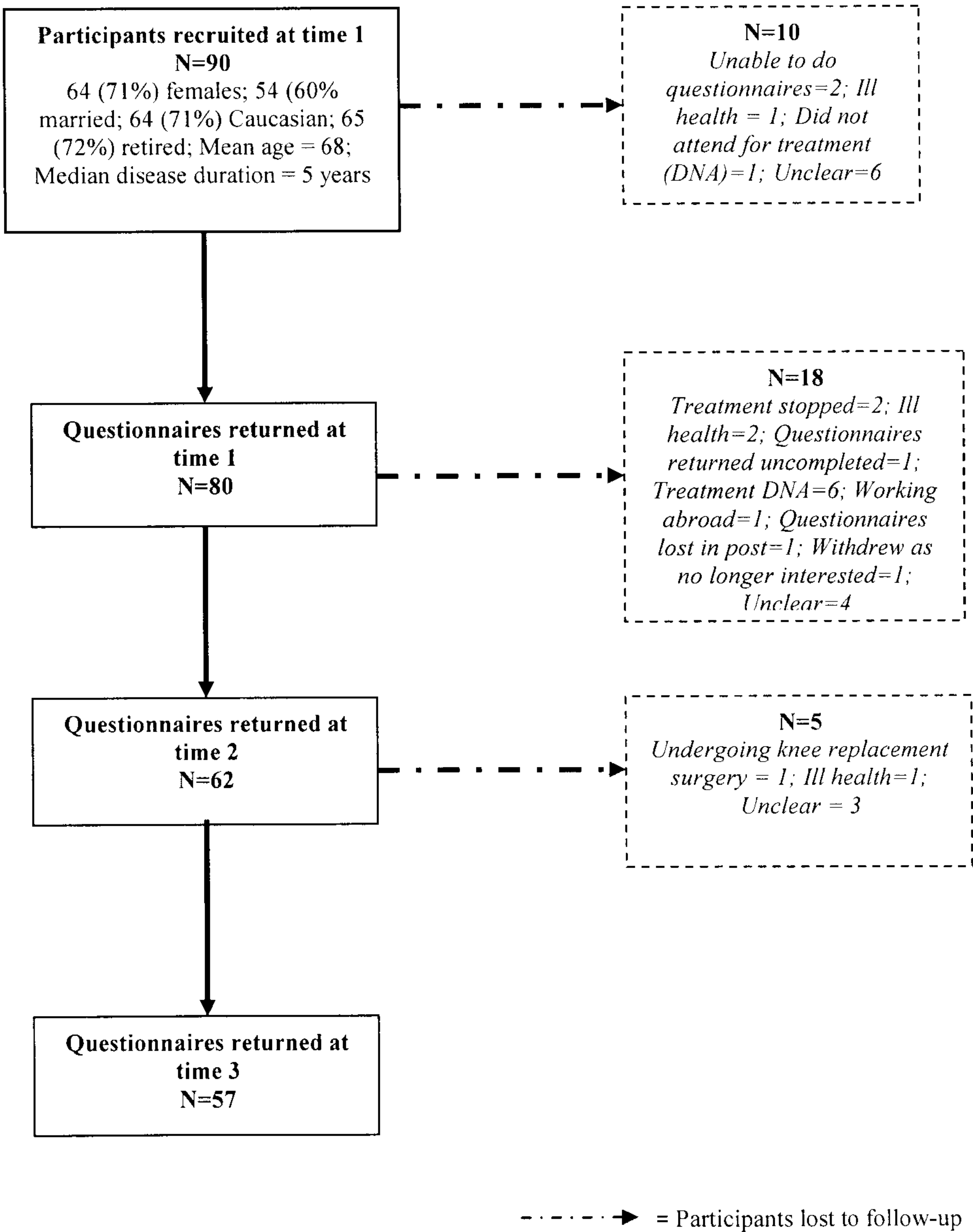
In the clinical trial participants were recruited from primary care, and randomised to one of three arms (individual or group). Participants in the rehabilitation arms received twelve sessions, twice a week for six weeks with each session lasting approximately 40 minutes. The sessions consisted of an individualised, progressive exercise programme, designed to address a range of issues, including: increase function; strengthen muscles; improve flexibility and mobility; improve coordination and balance; improve motor control. Each session also focused on a particular aspect of

self-management, such as diet or pain control. For a full description of the intervention programme see www.kcl.ac.uk/gppc/escape.

7.2.6 Response rates

Figure 7.2 shows the response rates for each timepoint of 57 cases had complete data (at all three time points), with 19 in each randomisation arm.

Figure 7.2 Response rates for each timepoint



7.3 CROSS-SECTIONAL ANALYSES

In the following sections, details of the participants, data handling strategies and missing data will be presented, and hypothesis 1 will be tested.

7.3.1 Participants

For the cross-sectional analyses pooled data were used. Table 7.2 illustrates the demographic information for the 90 participants who received the baseline questionnaires.

Table 7.2 Demographic information for participants given the baseline questionnaires

Variables	N=90	
Age	68 (<i>SD</i> 7.62, range 50-82)	
Disease duration (median)	5.00 years (range 0.25-60.00)	
Sex	Female	64 (71%)
	Male	26 (29%)
Marital status	Married	54 (60%)
	Widowed	16 (18%)
	Divorced	11 (12%)
	Single	7 (8%)
	Separated	1 (1%)
	Cohabiting	1 (1%)
Ethnic group	Caucasian	60 (66%)
	Black Caribbean	17 (19%)
	Black African	6 (7%)
	Indian	6 (7%)
	Pakistani	1 (1%)
Live alone?	No	63 (70%)
	Yes	27 (30%)
Accommodation	Owner occupied	57 (63%)
	Rented from local housing authority	32 (36%)
	Privately rented	1 (1%)
Employment	Retired/redundant	65 (72%)
	Employed full-time	13 (15%)
	Employed part-time	9 (10%)
	Unemployed and able to work	3 (3%)

Participants in the expectations study formed a subgroup from the larger intervention trial described in 7.2.5. To establish that the subgroup ($n=90$) and the main rehabilitation trial participants ($n=328$ who did not complete the KPBQ and activity self-report measures), were not significantly different, chi-square tests were conducted on the categorical data (e.g. marital status), an independent t-test was used to test for differences in mean age between the groups and a Mann-Whitney test was used to look for differences in disease duration.

Significantly more participants in the expectations study were married or cohabiting than in the main study (61% versus 46%), fewer were separated, divorced or single (21% versus 28%) and fewer were widowed (18% versus 26%) ($\chi^2(2) = 6.47, p < .05$, Cramer's $V=.12$). No significant differences were found between the groups on any of the other variables. There were no significant differences between the groups on sex ($\chi^2(1) = 0.20, p > .05$), ethnicity ($\chi^2(1) = 2.25, p > .05$), living alone ($\chi^2(1) = 1.59, p > .05$), accommodation ($\chi^2(1) = 1.61, p > .05$), employment ($\chi^2(1) = 0.25, p > .05$), age at study entry ($t(416) = -1.71, p > .05$) or disease duration ($U = 13979.50, p > .05$).

7.3.2 Cross-sectional measures

Table 7.3 shows the variables used in the cross-sectional analyses.

	Variables
Baseline Predictor Variables	Age
	Disease duration
	KPBQ (Illness expectations; perceptions of current condition; defensive optimism; perceived invulnerability)
	IPQ-R (Identity; timeline; consequences; personal control; treatment control; cyclical; coherence; emotion)
	IPQ-R Causal beliefs (Overwork; accident or injury; Chance or bad luck; hereditary; own behaviour)
	WOMAC (Pain; stiffness; function)
	HAD (Anxiety; depression)
	Self-Efficacy for Exercise Scale (Self-efficacy; barriers; benefits; outcome/impact of exercise)
Outcome Variables	Number of self-reported activities
	Frequency of self-reported activities
	Total self-reported activity levels

Table 7.3 Measures completed by cross-sectional participants

7.3.3 Data Handling for Hypothesis 1

Because these are cross-sectional hypotheses, the sample consists of all participants who completed baseline data ($N=80$) although numbers for the correlation matrix and regression models vary depending on missing data.

Histograms and boxplots for each variable were checked for normal distribution and the presence of outliers to ensure that assumptions of normality were not violated. Histograms indicated some skewness in the distribution of variables but only five were significantly skewed; benefits of exercise, outcome expectations (both negatively skewed), disease duration, number of activities and total activity levels (all positively skewed). When outliers for these variables were identified and the most extreme values moved inwards to the next point, all of the skewness statistics became non-significant except disease duration.

When the kurtosis statistics were checked eight variables were significantly kurtotic; the five significantly skewed variables, plus coherence, the accident or injury causal item, and number of regular activities. Removing the outliers for number of regular activities decreased kurtosis from 1.63 to -.55. For the coherence and accident variables, kurtosis fell within the 99% confidence interval (three standard deviations), a satisfactory distance to indicate that these variables were normally distributed. The disease duration variable was transformed using log transformation, with a constant of 1, because removing outliers did not bring it within a normal distribution and the kurtosis statistic was over 3 standard deviations. All variables then displayed a normal distribution.

7.3.4 Missing Data

Missing data on questionnaires completed at the assessment were kept to a minimum as measures could be checked. However, a greater number of items were omitted on the measures completed at home. When the distribution of KPBQ missing items was examined most of the missing items in the baseline data were in factor two which included items concerning previous treatment. Some participants may not have received any previous treatment, or for those randomised to the intervention arms may have been waiting until they had received the rehabilitation programme. This is supported by the number of missing items for that factor decreasing from 23 at baseline to 2 and 4 at time 2 and time 3 respectively. Factor 4 consisted of only 1 item therefore missing values could not be calculated.

Missing values for the KPBQ and IPQ-R data were handled using the person mean substitution method (Downey & King, 1998). For each factor with missing data a mean score could still be computed if there were scores for at least half of the items

in that factor (Hawthorne & Elliott, 2005). This method assumes the scores would be similar for items in each factor and it has advantages over methods such as least value carried forward in that scores are used from several items that are expected to be related.

For the KPBQ data, the amount of missing data went from 4% to 1% at time 1; 2% to 0% at time 2 and 5% to 4% at time 3. The missing data from the IPQ-R beliefs section decreased from 10% to 1% at time 1; 11% to 1% at time 2 and 9% to less than 1% at time 3. The use of this person mean substitution method is recommended over listwise deletion and item mean substitution, two commonly used methods for dealing with missing data (Hawthorne & Elliott, 2005).

The IPQ-R causal beliefs section is not divided into factors, so the frequency with which items were endorsed was examined to gauge whether missing items were likely to have been positively endorsed. For cases with missing data the “most important causes” section was examined to see whether any missing items were given as important causes. The mean number of items endorsed by cases with complete data was calculated (mean=3.69, $SD=1.83$) to give an indication of expected number of items endorsed (the total number of causal items was normally distributed).

For the activity data, participants were asked to indicate the activities they had taken part in during the preceding month and give the frequency and duration of these activities. Where data regarding frequency or duration were missing, the median for the specific activity was calculated and substituted, then the mean for all activities

combined as frequency and duration related to, for example walking, might be expected to be very different to that for dancing.

7.3.5 Causal Beliefs Data

IPQ-R causal beliefs data are usually factor analysed and the factors then used as predictor variables. However, a sample size of 80 is unlikely to produce a stable solution, so it was recommended that single items be selected instead (French, 2005). Table 7.4 shows the frequency table of responses for the causal items. Items marked with an asterisk were selected for use as predictor variables as they fell in the mid-range of endorsed responses, and were hypothesised to be influential causal beliefs.

Table 7.4 Frequency table for items endorsed in causal beliefs section of IPQ-R

Item	N endorsed (agree or strongly agree)	% endorsed (agree or strongly agree)
Wear and tear on my joint	67	84
Ageing	60	75
Overwork*	40	50
Accident or injury*	29	36
Chance or bad luck*	18	23
Poor medical care in my past	15	19
Hereditary*	14	18
My own behaviour*	12	15
Stress or worry	10	13
Diet or eating habits	8	10
My emotional state	5	6
Altered immunity	4	5
Pollution in the environment	3	4
Alcohol	2	3
Germ or virus	2	3
Family problems or worries	1	1
My mental attitude	1	1
Smoking	1	1
My personality	0	0

*Items used as predictor variables

7.3.6 Analysis

A 1-tailed correlation matrix was produced using all the variables listed in table 7.2 to detect significant correlations between the predictor and outcome variables. This

gives an indication of items suitable for use in a multiple regression model and also allows for the detection of collinearity (see section 7.3.8.1); any significant correlations between the predictor variables indicate they are measuring similar constructs and may enable the number of predictor variables used in the regression model to be reduced, increasing robustness. Following the correlation matrix, a regression model was performed to examine the amount of variance explained by the expectation variables.

7.3.7 Results

7.3.7.1 Correlation Matrices

Table 7.5 shows the significant correlations between the predictor and outcome variables. The significant correlations were in the expected directions, for example positive illness expectations were associated with a greater amount of self-reported activity, whilst a higher number of perceived consequences of the condition were associated with a lower activity level score.

Table 7.5 Significant correlations between predictor and outcome variables (Pearson correlations and significance levels (1-tailed))

Predictor variables	Number of activities	Frequency of activities	Total activities
Illness expectations (KPBQ factor 1)	.17 .13	.26* .02	.26* .02
Defensive optimism (KPBQ factor 3)	-.07 .26	-.02 .44	-.20* .04
IPQ-R Number of symptoms	-.23* .02	-.09 .21	-.11 .19
IPQ-R Consequences	-.21* .03	-.17 .07	-.29** .01
WOMAC pain	-.06 .30	-.15 .10	-.22* .03
WOMAC function	-.14 .11	-.20* .04	-.26** .01
WOMAC total	-.12 .14	-.20* .04	-.26** .01
HAD depression	-.08 .24	-.15 .10	-.20* .04
Self-efficacy expectations	.21* .03	.19* .05	.23* .05
Benefits of exercise	.14 .12	.15 .10	.21* .04
Outcome expectations	.14 .12	.11 .17	.24* .02
Self-efficacy total	.20* .03	.20* .04	.28** .01

*Correlation is significant at the .05 level, **Correlation is significant at the .01 level

Number of Activities

The number of activities was positively correlated with self-efficacy expectations and total exercise beliefs, but negatively correlated with number of symptoms and perceived consequences of knee pain.

Frequency of Activities

The frequency of activities was positively correlated with future beliefs, self-efficacy expectations and total exercise beliefs, but negatively correlated with the number of symptoms and the WOMAC total score.

Total Activity Levels

The total amount of activity was positively correlated with future beliefs, self-efficacy expectations, perceived benefits of exercise, outcome expectations and total exercise beliefs, but negatively correlated with defensive optimism, perceived consequences, pain, functional problems, total WOMAC score, and depression.

In addition, significant correlations arose between the different activity variables (table 7.6). This is partly due to the way that total activity levels were calculated.

Table 7.6 Correlations between the outcome variables (Pearson correlations & significance levels (1-tailed))

Correlations between outcome variables	Number of activities	Frequency of activities	Total activity level
Number of activities	1 -		
Frequency of activities	.67** .00	1 -	
Total activity level	.42** .00	.69** .00	1 -

**Correlation is significant at the .01 level

The correlation matrix was checked for collinearity in the WOMAC and the beliefs about exercise measures. Table 7.7 shows significant inter-correlations between the WOMAC dimensions and total score, strongly suggesting that the total WOMAC score would accurately represent scores on pain, stiffness and function dimensions. The correlation between function and total score was particularly high, which is unsurprising as the function subscale contributes significantly to the total score.

Table 7.7 Inter-correlations of WOMAC measure (Pearson correlations & significance levels (1- tailed))

WOMAC variables	Pain	Stiffness	Function	Total score
Pain	1 -			
Stiffness	.65** .00	1 -		
Function	.77** .00	.76** .00	1 -	
Total score	.85** .00	.81** .00	.99** .00	1 -

*Correlation is significant at the .05 level, **Correlation is significant at the .01 level

Significant inter-correlations were seen between the beliefs about exercise subscales and total (table 7.8). Whilst the total score could have been used as a predictor variable, the separate self-efficacy and outcome scales were used to enable examination of the influence of different types of expectations.

Table 7.8 Inter-correlations of beliefs about exercise measure (Pearson correlations & significance levels (1-tailed))

Exercise beliefs variables	Self-efficacy expectations	Barriers	Benefits	Outcome expectations	Total score
Self-efficacy expectations	1 -				
Barriers	.27** .01	1 -			
Benefits	.25* .03	.33** .00	1 -		
Outcome expectations	.33** .00	.21* .03	.52** .00	1 -	
Total score	.69** .00	.50** .00	.72** .00	.77** .00	1 -

*Correlation is significant at the .05 level, **Correlation is significant at the .01 level

Because the KPBQ is a new measure, the correlations between the four beliefs factors and the other variables were inspected to gain an understanding of which variables correlated significantly with each factor (see table 7.9).

Table 7.9 Correlations between KPBQ factors and other variables (Pearson correlations & significance levels (1-tailed))

Predictor variables	Illness expectations (Factor 1)	Current condition (Factor 2)	Defensive optimism (Factor 3)	Perceived invulnerability (Factor 4)
Age	-.00 .49	.24* .02	.30** .00	-.13 .13
Illness expectations	1 -	.43** .00	.13 .13	-.12 .15
Current condition	.43** .00	1 -	.22* .03	-.22* .03
Defensive optimism	.13 .13	.22* .03	1 -	-.10 .20
Perceived invulnerability	-.12 .15	-.22* .03	-.10 .20	1 -
IPQ-R Number of symptoms	-.35** .00	-.43** .00	-.17 .07	.12 .16
IPQ-R Timeline	-.56** .00	-.32** .00	-.10 .18	.04 .36
IPQ-R Consequences	-.34** .00	-.40** .00	-.17 .07	.19* .04
IPQ-R Personal control	.19* .05	.14 .12	.13 .13	-.27** .01
IPQ-R Treatment control	.22* .03	.07 .27	.07 .28	.18 .06
IPQ-R Cyclical	-.15 .10	-.20* .04	-.28** .01	.05 .32
IPQ-R Emotion	-.31** .00	-.34** .00	-.13 .13	.01 .48
IPQ-R Total causal attributions	-.21* .03	-.25** .01	-.18* .05	-.09 .23
Hereditary cause	-.23* .02	-.12 .15	-.08 .23	-.15 .10
Chance	.02 .43	-.20* .05	-.08 .24	-.02 .42
WOMAC pain	-.25** .01	-.41** .00	-.04 .37	.07 .26
WOMAC stiffness	-.31** .00	-.32** .00	-.23* .02	-.01 .48
WOMAC function	-.23* .02	-.31** .00	-.09 .23	.02 .45
WOMAC total	-.25** .01	-.35** .00	-.09 .21	.02 .42
HAD anxiety	-.19* .05	-.11 .17	-.08 .25	-.16 .07
HAD depression	-.20* .04	-.09 .23	-.10 .19	.03 .39
Mean frequency of activities	.26** .01	.14 .12	-.02 .44	-.02 .44
Total activity (frequency and duration)	.26** .01	.18 .06	-.20* .04	-.06 .31

*Correlation is significant at the .05 level

**Correlation is significant at the .01 level

Illness expectations (Factor 1)

More positive beliefs about the future were significantly associated with the following: more positive perceptions about current condition; fewer symptoms; shorter timeline; fewer consequences; greater personal control; greater treatment control; less emotional impact; fewer attributed causes; condition less likely to be seen as hereditary; less pain, stiffness, functional problems and lower total WOMAC scores; less anxiety and depression; higher activity frequency and total activity levels.

Perceptions of Current Condition (Factor 2)

More positive perceptions about current condition were associated significantly with: older age; more optimism; development of the condition more likely to be expected; fewer symptoms; shorter timeline; fewer consequences; less likely to be cyclical; lower emotional impact; fewer causal attributions; less likely to be perceived as being caused by chance; less pain, stiffness, functional problems and lower total WOMAC scores.

Defensive Optimism (Factor 3)

More optimistic beliefs were significantly associated with: older age; condition less likely to be perceived as being cyclical; fewer causal attributions; less stiffness; fewer total activities.

Perceived Invulnerability (Factor 4)

A greater expectation of developing OA (i.e. lower perceived invulnerability) was significantly associated with: fewer perceived consequences; higher beliefs for personal control.

There were no significant correlations between any KPBQ factor and any beliefs about exercise factor.

7.3.8 Hypothesis 1 – Regression Models

The following hypotheses were investigated:

General Primary Hypothesis:

1. Baseline illness expectations will be significantly related to levels of baseline self-reported activity.

Specifically:

1a. Participants with more positive baseline expectations about their condition, and positive baseline current perceptions of their condition, will have higher levels of self-reported activity.

1b. Participants with higher levels of self-reported defensive optimism and perceived invulnerability (i.e. who did **not** expect to develop knee pain) will have lower levels of self-reported activity.

1c. Participants with higher levels of self-efficacy and higher expectations of exercise outcome will have higher levels of self-reported activity.

1d. Illness expectations will contribute significantly to the prediction of activity levels, after controlling for outcome and self-efficacy expectations.

7.3.8.1 Regression Model 1

The total activity variable correlated significantly with more predictor variables than either number of activities or frequency, so was used as the single outcome variable.

It was hypothesised that beliefs about knee pain, beliefs about own ability to exercise and beliefs about exercise outcome would explain a significant amount of the variance in the amount of exercise activity performed, so only the expectation

variables which correlated significantly with total activity were entered into the model. They were: illness expectations (KPBQ factor 1); defensive optimism (KPBQ factor 3); self-efficacy for exercise; outcome expectations of exercise.

The recommended sample size for regression differs according to the size of the expected effect. When looking for a large effect, with alpha set at 0.05, power at 0.8 (i.e. 80% chance of detecting a significant result if there is an effect of the specified size in the sampled population (Miles & Shevlin, 2001)), and with 4 predictors, 40 participants are required; for a medium effect between 85-90 participants, and for a small effect approximately 600 participants would be required! Complete data for 76 participants were used in the analyses, which are sufficiently powered to detect a medium to large effect in both the first and second regression models, which contain 4 and 6 predictor variables respectively. A scatterplot was produced for each predictor variable against total activity to confirm they were linearly related and ensure that assumptions of linearity were not violated.

The four expectations variables were entered into a hierarchical regression model to examine their influence on total activity. Previous work indicated that self-efficacy and outcome expectations were more influential than illness, or risk, expectancies (Schwarzer & Fuchs, 1996; Sniehotta et al., 2005) and came from a more established measure than the new KPBQ, so were entered into the model first. Table 7.10 displays the findings for the regression model (see appendix 6 for the full output). When just self-efficacy and outcome expectations were entered into the model, neither were significant predictors of self-reported activity levels (self-efficacy, $B = .16, p > .05$ and outcome, $B = .19, p > .05$) and accounted for only 8% of the variance in activity levels. Entering illness expectations and defensive optimism into the

model led to a significant increase in variance accounted for (R^2 change = .13, $p \leq .01$) and there were significant effects for both illness expectations ($B = .30$, $p \leq .01$) and defensive optimism ($B = -.23$, $p < .05$). ANOVA model 1 = $F(2,73)=3.23$, $p < .05$ & model 2 = $F(4,71)=4.72$, $p < .01$ (see appendix 6).

Table 7.10 Regression analysis with expectations variables as predictors of total self-reported activity levels

Variable	R^2	R^2 change	F change	Df	B^a
Step 1	.08		3.23*	2, 73	
Self-efficacy expectations					.16
Outcome expectations					.18
Step 2	.21	.13	5.79**	2, 71	
Self-efficacy expectations					.21
Outcome expectations					.17
Illness expectations					.30**
Defensive optimism					-.23*

* $p \leq .05$, ** $p \leq .01$ ^aStandardized regression coefficients are based on the final regression equation

The collinearity statistics were assessed to check that the predictor variables were independent. The tolerance scores were all above .2 and the average VIF statistic was 1.12, so the regression was not biased (Field, 2005). However, the eigenvalues were all small and the condition index values for dimensions 4 and 5 were large (12.91 and 29.81 respectively), indicating possible collinearity. Despite this, the variance proportion for each variable loaded significantly onto different dimensions indicating that collinearity was not a problem. In addition, dimensions 4 and 5 related to self-efficacy and outcome expectations, which were from the same questionnaire, so a degree of overlap may be expected.

Scatterplots of the standardized predicted values against the standardized residuals and the studentized residuals were obtained to check assumptions of homoscedasticity (that the residuals at each level of the predictor variables have similar variances). The points were randomly distributed around zero indicating that

the assumption of homoscedasticity was met (Field, 2005). In addition a histogram and P-P plot were generated to check for normal distribution of the residuals (figures 7.3 and 7.4). It was unclear whether the standardized values differed significantly from normality so a Kolmogorov-Smirnov (K-S) test was performed. The K-S statistic of .10 ($p < .05$) differed significantly from the normal distribution; the findings have limited generalisability and should be interpreted with caution.

Figure 7.3 Histogram of the regression standardized residuals for model 1

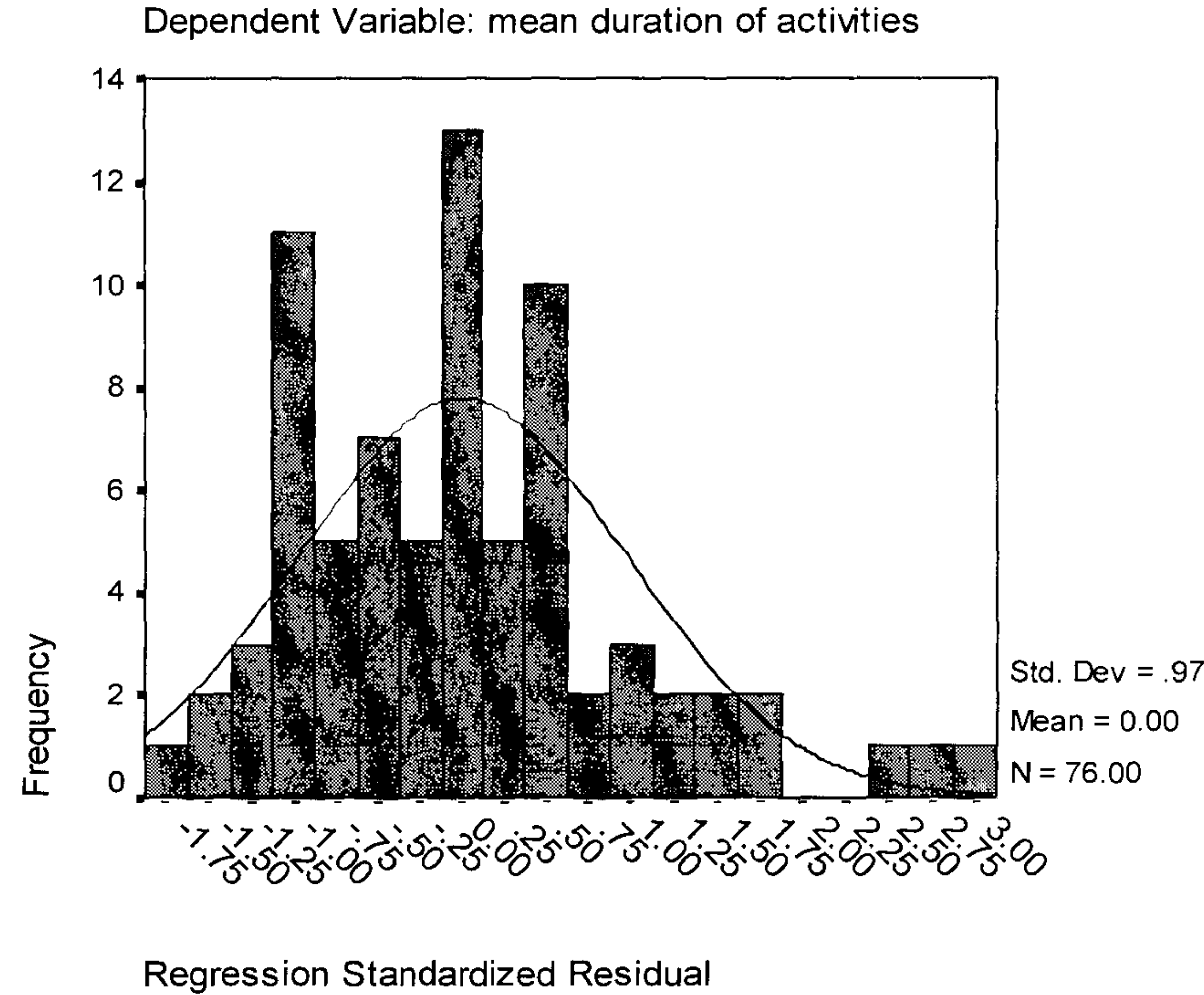
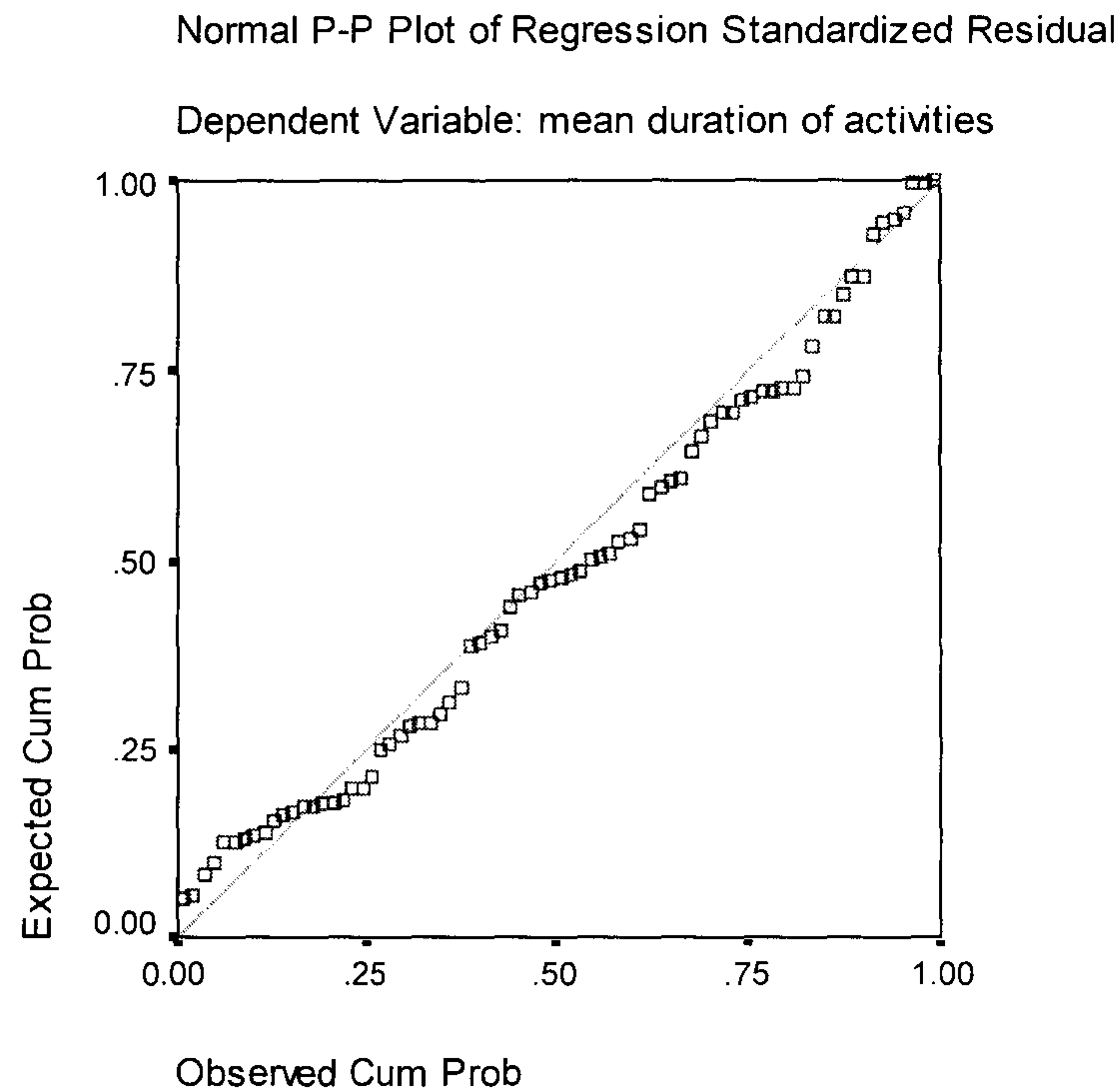


Figure 7.4 P-P plot of the regression standardized residuals for model 1



Casewise diagnostics were produced to highlight any extreme cases that had a significant influence on the model. Ninety five percent of cases should have residuals which fall within -2 and +2 (Field, 2005). Three cases (4%) with residuals between 2 and 3 were identified, and reflect what would be expected from a reasonably accurate model. The influence of cases on the model was assessed using Mahalanobis Distance and Cook's Distance. Mahalanobis Distance measures the distance of cases from the mean of the predictor variable. For this sample size, with three predictors, a cut-off point of 15 is appropriate. In this sample, one case was over this value (20.41), and may have had an undue influence upon the model. Cook's Distance is a measure of the overall influence of a single case on the model as a whole. Values over 1 indicate disproportionate influence and all cases fell well below this (the highest value was 0.11). Additionally, DFBeta values for intercept and the three predictor variables all fell between -1 and +1 indicating that no case had undue influence on the model.

Overall this is a robust, reasonably accurate model, which predicts a significant amount of variance in activity, with the most influential predictor being the illness expectations factor. The findings partially support hypothesis 1; participants with more positive expectations about their knee pain reported significantly higher activity levels, whilst those who were generally more optimistic reported lower activity. Self-efficacy and outcome expectations did not explain a significant amount of variance in the final model, which contrasts with previous work, and will be discussed in more detail in section 7.6. The whole model accounted for 21% of the sample variance, so a second regression was performed using expectations variables and other variables, in an attempt to explain a greater amount of variance in activity levels.

7.3.8.2 Regression Model 2

A second model was tested which included the remaining variables that had correlated significantly with total activity. The sample size meant that using eleven predictor variables would have compromised the reliability of the model, so the total WOMAC score was entered as pain and function correlated highly with this variable. Similarly the total scores from the self-efficacy for exercise scale were used as self-efficacy, outcome and benefits subscales all correlated significantly with total, and self-efficacy and outcome expectation variables were not significant in the previous model. The predictor variables entered into the hierarchical regression model were:

- Step 1: WOMAC total scores
- Step 2: Illness expectations
 - Defensive optimism
 - IPQ-R consequences
 - HAD depression
 - Beliefs about exercise scores

The WOMAC score was entered first, as pain and function scores were hypothesised to be important in predicting activity levels. Table 7.11 displays the findings for the regression analysis (see appendix 6 for the output).

Table 7.11 Regression analysis with self-report variables as predictors of total self-reported activity levels

	Variable	R^2	R^2 change	F change	Df	B^a
Step 1	Total WOMAC scores (pain, stiffness, function)	.07		5.22*	1, 73	-.26*
Step 2		.25	.18	3.22**	5, 68	
	Total WOMAC scores					-.04
	Illness expectations					.26*
	Defensive optimism					-.24*
	IPQ-R consequences					-.16
	HAD depression					-.01
	Beliefs about exercise					.26*

* $p \leq .05$, ** $p \leq .01$ ^aStandardized regression coefficients are based on the final regression equation

The WOMAC total score was a significant predictor of self-reported activity levels ($B = -.26$, $p < .05$) and accounted for 7% of the variance. The remaining 5 predictor variables increased the variance accounted for to 25% (R^2 change = 0.18, $p \leq .01$), and there were significant effects for illness expectations ($B = .26$, $p < .05$), defensive optimism ($B = -.24$, $p < .05$) and beliefs about exercise scores ($B = .26$, $p < .05$). In the second model WOMAC score no longer significantly predicted self-reported activity. Consequences and depression scores did not significantly increase variance accounted for.

The Durbin-Watson value of 2.39 indicated that the model fulfilled the assumption of independence of errors. Model 1 was significant at $p < .05$, model 2 significant at $p \leq .01$. The significant variables, shown in table 7.11, were the 2 KPBQ expectations factors (1 & 3) and the self-efficacy total score (the WOMAC total

from model 1 became non-significant when the remaining variables were added). All the tolerance statistics were above .2 and all VIF values were under 2 (the mean was 1.42), therefore collinearity did not appear to be a problem with these variables, because with the exception of the two KPBQ items, each variable came from a separate measure.

The maximum value of Mahalanobis Distance was 22.03, and four other cases were either close to or above the recommended cut-off point of 15. However, Cook's Distance for all cases was well below 1 (the maximum was .14), indicating that no case had undue influence on the model as a whole. An examination of the histogram of normal distribution of the regression standardized residual and the p-p plot (see figures 7.5 and 7.6) indicated a positive skew, although the significance was unclear. The K-S value was again .10 ($p < .05$), indicating that the distribution differed significantly from normal. Scatterplots for the predicted values against the standardized residuals and against the studentized residuals were distributed randomly and clustered around zero, confirming the assumption of homoscedasticity.

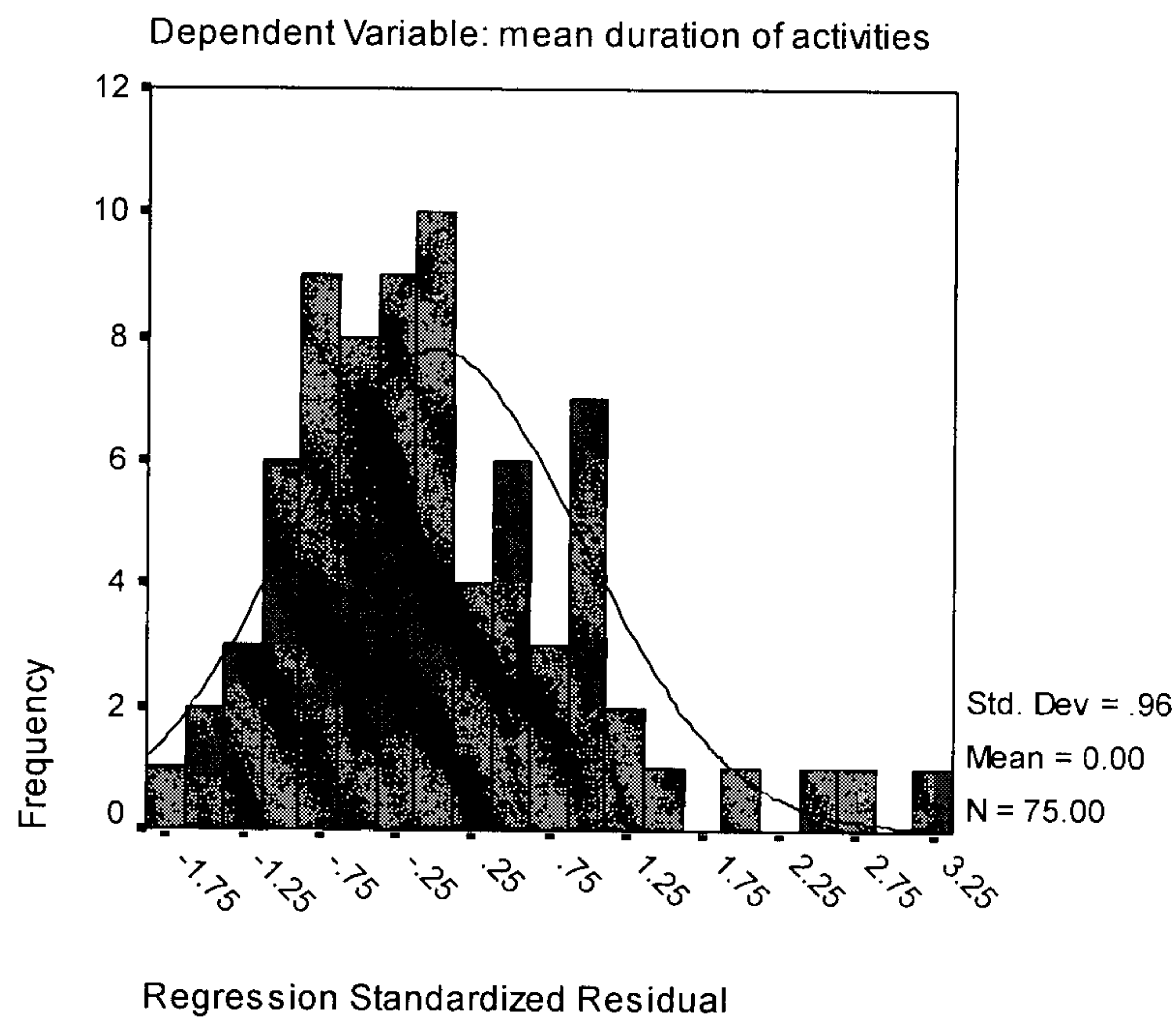


Figure 7.5 Histogram of the regression standardized residuals for model 2

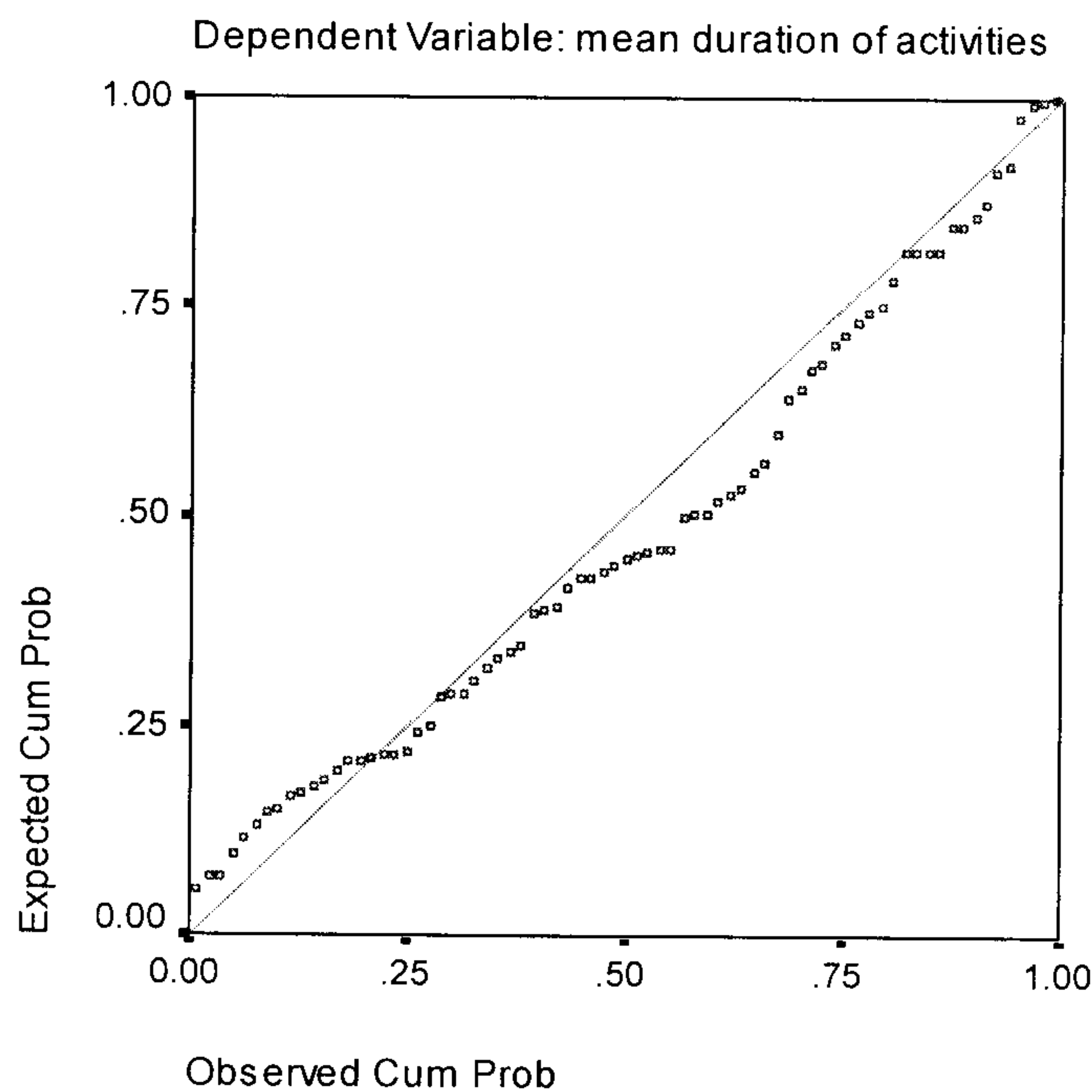


Figure 7.6 P-P plot of the regression standardized residuals for model 2

This model accounted for 25% of the sample variance in total activity levels; 4% more than that explained by model 1, which included only expectation beliefs.

However, 75% of the variance in activity was still unaccounted for. The findings are discussed in section 7.6.

7.4 LONGITUDINAL ANALYSES – SELF-REPORTED ACTIVITY LEVELS

The findings from the cross-sectional models are useful in that they provide information on the relationship between expectations, other predictor variables and self-reported activity. However, they can provide no information on cause and effect due to their cross-sectional nature and so individuals may have positive illness expectations and lower defensive optimism because they have high activity levels. The next section describes two longitudinal regression models designed to assess predictors of self-reported activity using baseline variables.

7.4.1 Longitudinal Hypotheses – Regression Models

Baseline illness expectations and other KPBQ variables will account for significant levels of variance in activity levels at time 2 and time 3.

7.4.2 Participants

The fifty seven participants were from the same cohort of 90 described in section 7.3.1, but had completed questionnaires at all three timepoints (time 1, time 2 and time 3) (see fig 7.2 for the withdrawal rate at each timepoint).

Participant details are shown in table 7.12.

Variables	N=57	
Age	67 (SD 7.67), range (50-81)	
Disease duration (median)	6.00 years (range 0.33-60.00)	
Sex	Female	41 (72%)
	Male	16 (28%)
Marital status	Married	35 (61%)
	Widowed	9 (16%)
	Divorced	5 (9%)
	Single	6 (10%)
	Separated	1 (2%)
	Cohabiting	1 (2%)
Ethnic group	Caucasian	42 (74%)
	Black Caribbean	8 (14%)
	Black African	4 (7%)
	Indian	3 (5%)
Live alone?	No	39 (68%)
	Yes	18 (32%)
Accommodation	Owner occupied	37 (65%)
	Rented from local housing authority	19 (33%)
	Privately rented	1 (2%)
Employment	Retired/redundant	39 (69%)
	Employed full-time	11 (19%)
	Employed part-time	4 (7%)
	Unemployed and able to work	3 (5%)

Table 7.12 Demographic details of participants who completed questionnaires at all time points

To establish that no significant differences existed between those who completed the questionnaires at all three time points and those who did not, chi-square tests were conducted on the categorical data (e.g. marital status), whilst independent t-test and Mann-Whitney tests were used to test for differences in mean age and disease duration respectively. No significant differences were found between those completing all three visits and those who did not, for any of the demographic variables listed in table 7.1.

In the clinical trial participants were randomised to one of three arms; group intervention, individual intervention or control. Between-group error bars indicated that the groups did not differ significantly on either time 2 or time 3 activity, so the data for the three groups were pooled (see figures 7.7 and 7.8).

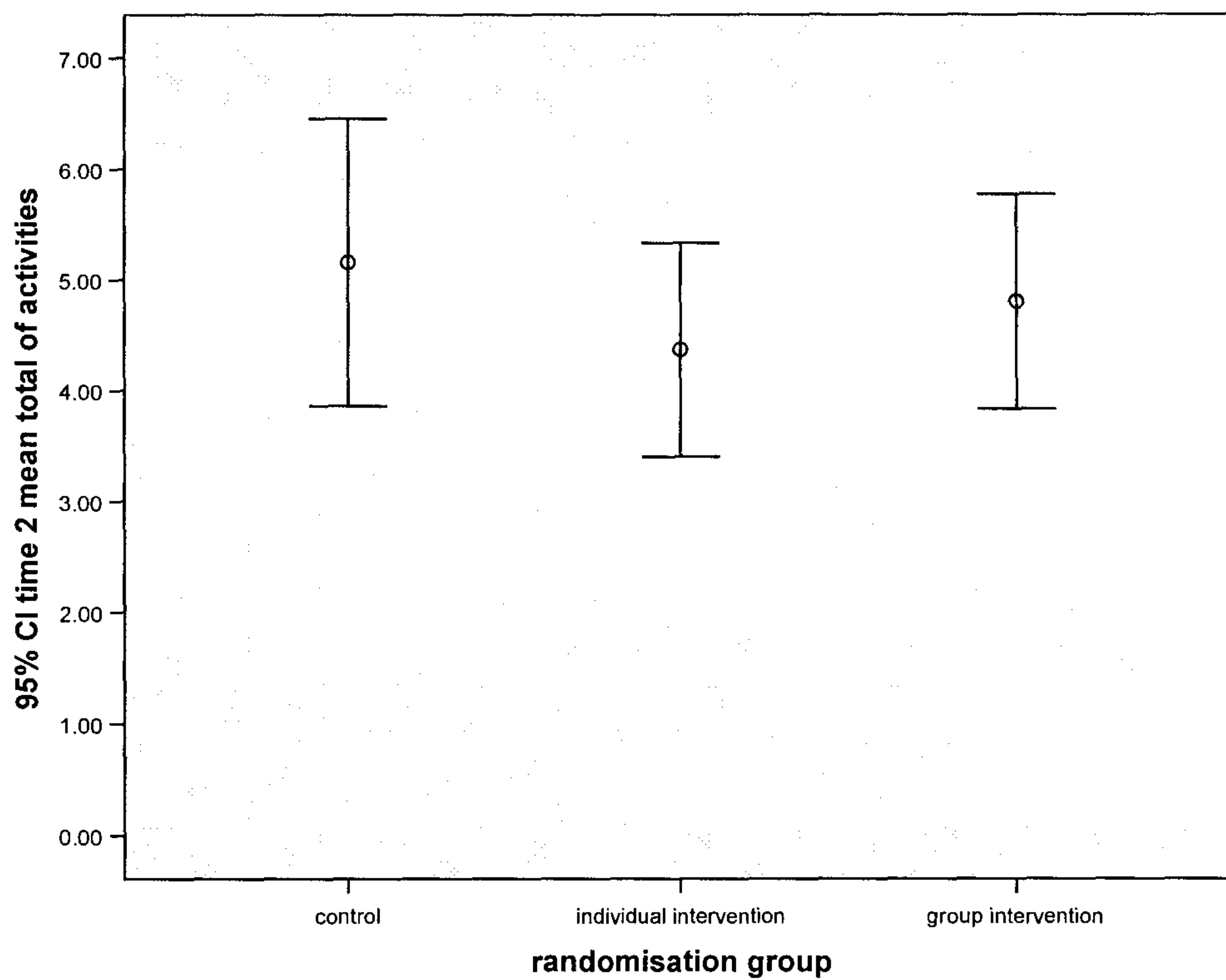


Figure 7.7 Error chart for time 2 activity levels

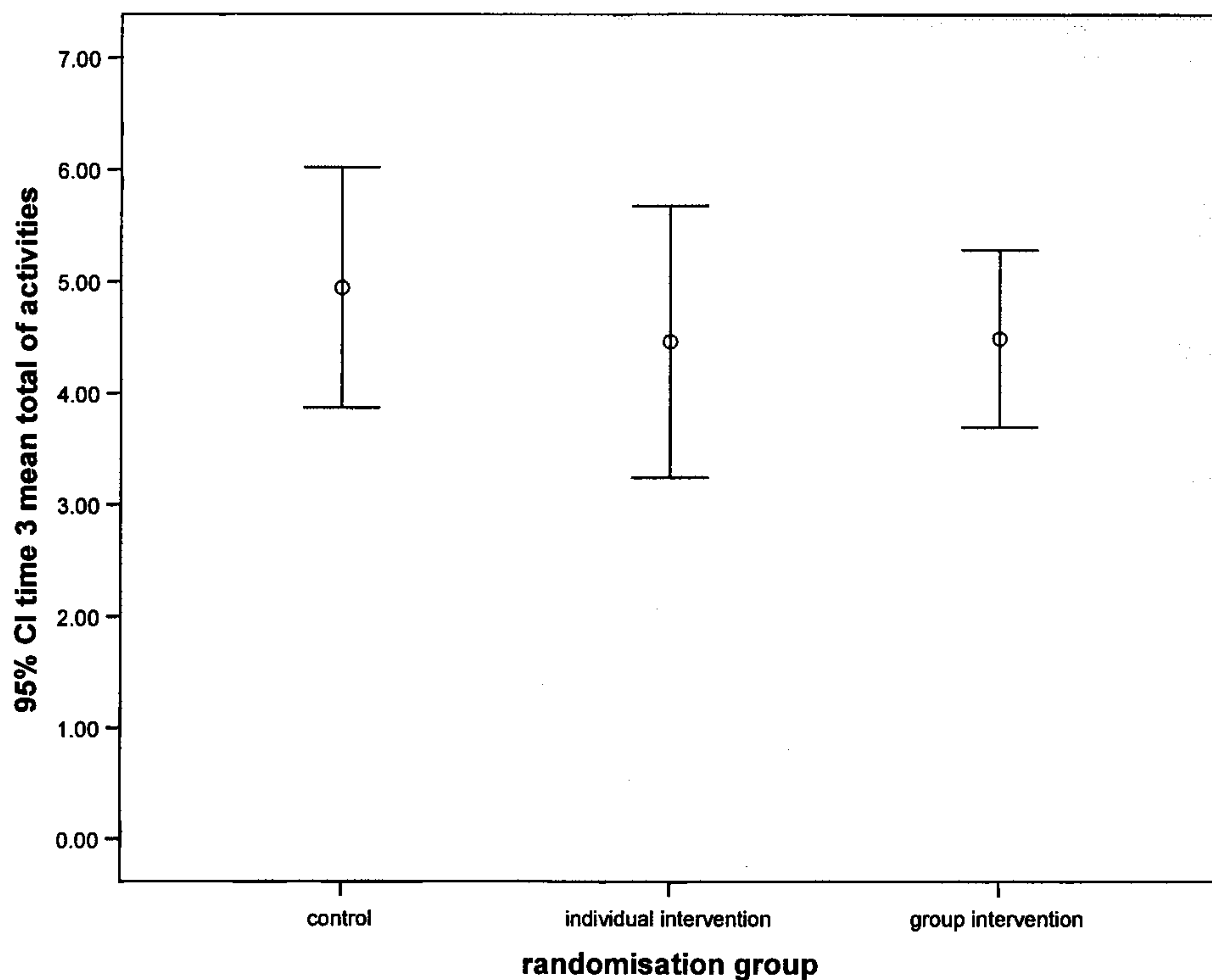


Figure 7.8 Error chart for time 3 activity levels

The number of participants (57) means that the regression analyses are powered to detect a large effect for a maximum of ten predictor variables (Miles & Shevlin, 2001).

7.4.3 Measures

The measures used in these analyses are the same as those described in table 7.3, except for number and frequency of self-reported activity, which were not used in these analyses.

7.4.4 Data Handling

To ensure that the data for the longitudinal analyses were normally distributed, means, medians, histograms and skewness and kurtosis statistics were examined for all baseline variables. All variables were within one standard deviation with the

exception of anxiety (skewed), illness expectations and illness coherence (both kurtotic). Removing an outlier brought illness expectations well within one standard deviation and anxiety within two standard deviations. Illness coherence had no obvious outliers so was left unchanged. Its value was within two standard deviations (2.34), which, given the small sample size was deemed satisfactory (Field, 2005).

7.4.5 Missing Data

Missing data were dealt with as described in 7.3.4.

7.4.6 Analysis

As in section 7.3.6 one-tailed correlation matrices between all baseline predictor variables and activity levels at time two and time three were produced to identify significant correlations and therefore suitable variables for the regression model. Following this, regression models were performed to examine the amount of variance in time two and time three activity explained by the baseline variables.

7.4.7 Results

7.4.7.1 Correlation Matrices for time 2 activity

Three baseline variables correlated significantly with time 2 activity levels; activity levels, personal control and treatment control (all positive correlations). Whilst illness expectations and defensive optimism were not significantly correlated with time 2 activity, they were entered into the regression model to explore their influence on the outcome variable and because they were significant in the cross-sectional model.

7.4.7.2 Regression model for time 2 activity

Baseline activity was entered into the first step of the hierarchical regression model as it was expected to have a strong relationship with time 2 activity, the control variables were entered at step 2, and the expectations variables at step 3. Table 7.13 shows the regression table for time 2 activity (see appendix 6 for the full output). At the first step baseline activity was a significant predictor of time 2 activity ($R^2 = .07$, $p < .05$) and accounted for 7% of the variance in activity levels. When personal control and treatment control were entered there was no significant increase in variance in self-reported activity levels (R^2 change = .08, $p > .05$), and no increase was seen when illness expectations and defensive optimism were entered at step 3 (R^2 change = .04, $p > .05$). ANOVA model 1 = $F(1,55)=3.88$, $p \leq .05$, model 2 = $F(3,53)=3.06$, $p < .05$, and model 3 = $F(5,51)=2.31$, $p > .05$). The final model accounted for 18% of the variance in time 2 activity but only baseline activity accounted for a significant amount of the variance.

Table 7.13 Regression analysis with baseline variables as predictors of time 2 total self-reported activity levels

	Variable	R^2	R^2 change	F change	Df	B^a
Step 1		.07		3.88*	1, 55	
	Total activity					.26*
Step 2		.15	.08	2.54	2, 53	
	Total activity					.25
	Personal control					.21
	Treatment control					.14
Step 3		.18	.04	1.15	2, 51	
	Total activity					.33*
	Personal control					.19
	Treatment control					.18
	Illness expectations					-.16
	Defensive optimism					.15

* $p \leq .05$ ^aStandardized regression coefficients are based on the final regression equation

The Durbin-Watson value of 1.94 was close to 2 and fulfilled the assumption of independence of errors. When collinearity was assessed all tolerance scores were over .2, and the average VIF score was 1.23 indicating that the predictor variables were independent (Field, 2005). However, the eigenvalues were small and the condition index values large, and variance proportions for activity and treatment control did not load heavily onto one dimension, so some collinearity may be present. Scatterplots of the standardised predicted values against standardised residuals and studentised residuals showed that the points were normally distributed around zero, and therefore the assumption of homoscedasticity was met (Field, 2005). Normal distribution of the residuals in the histogram and p-p plots indicated that the variables were normally distributed (see figures 7.9 and 7.10), and the K-S statistic of .10 ($p > .05$) indicated that the findings are generalisable.

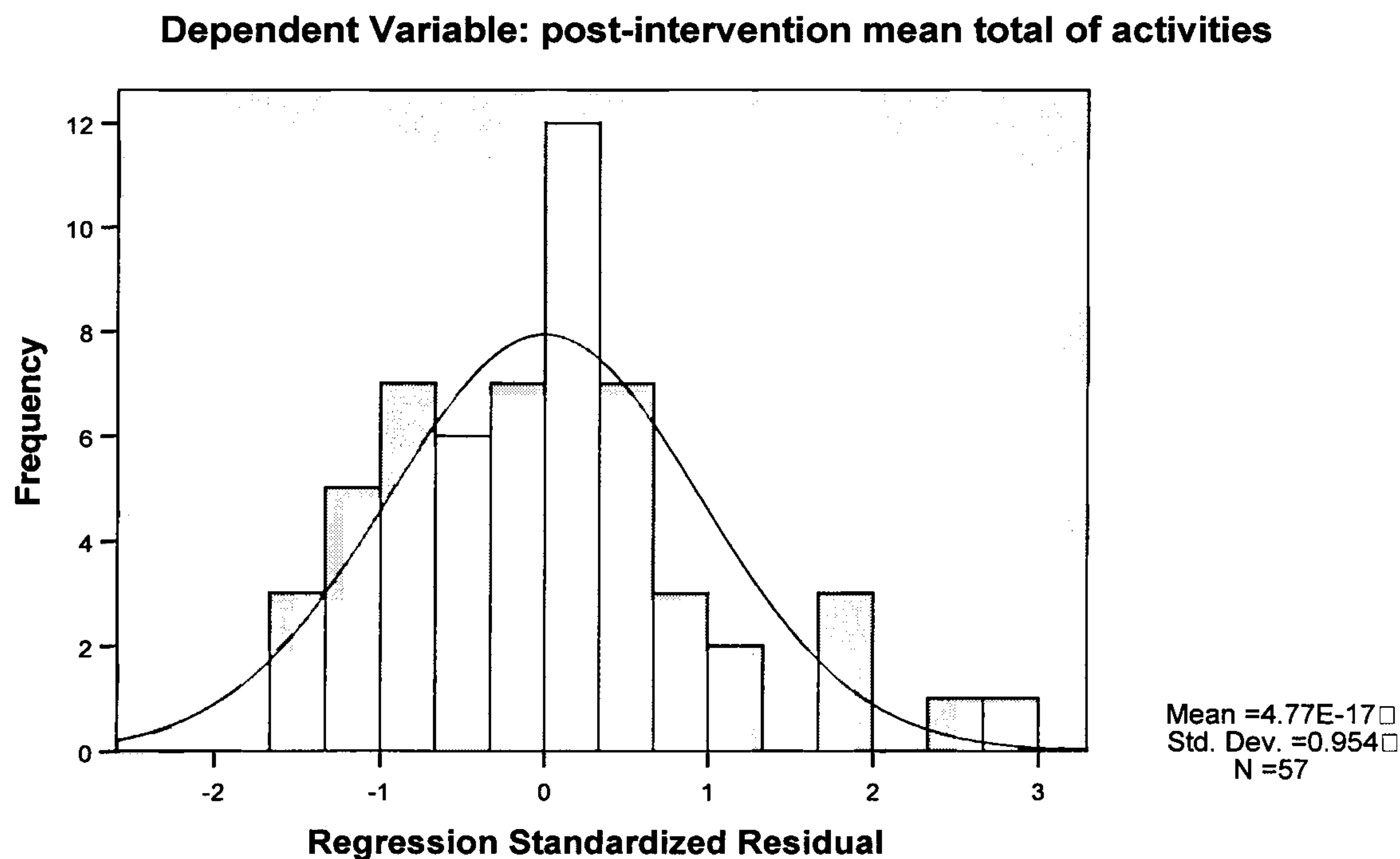


Figure 7.9 Histogram of the regression standardized residuals for time 2 activity model

Dependent Variable: post-intervention mean total of activities

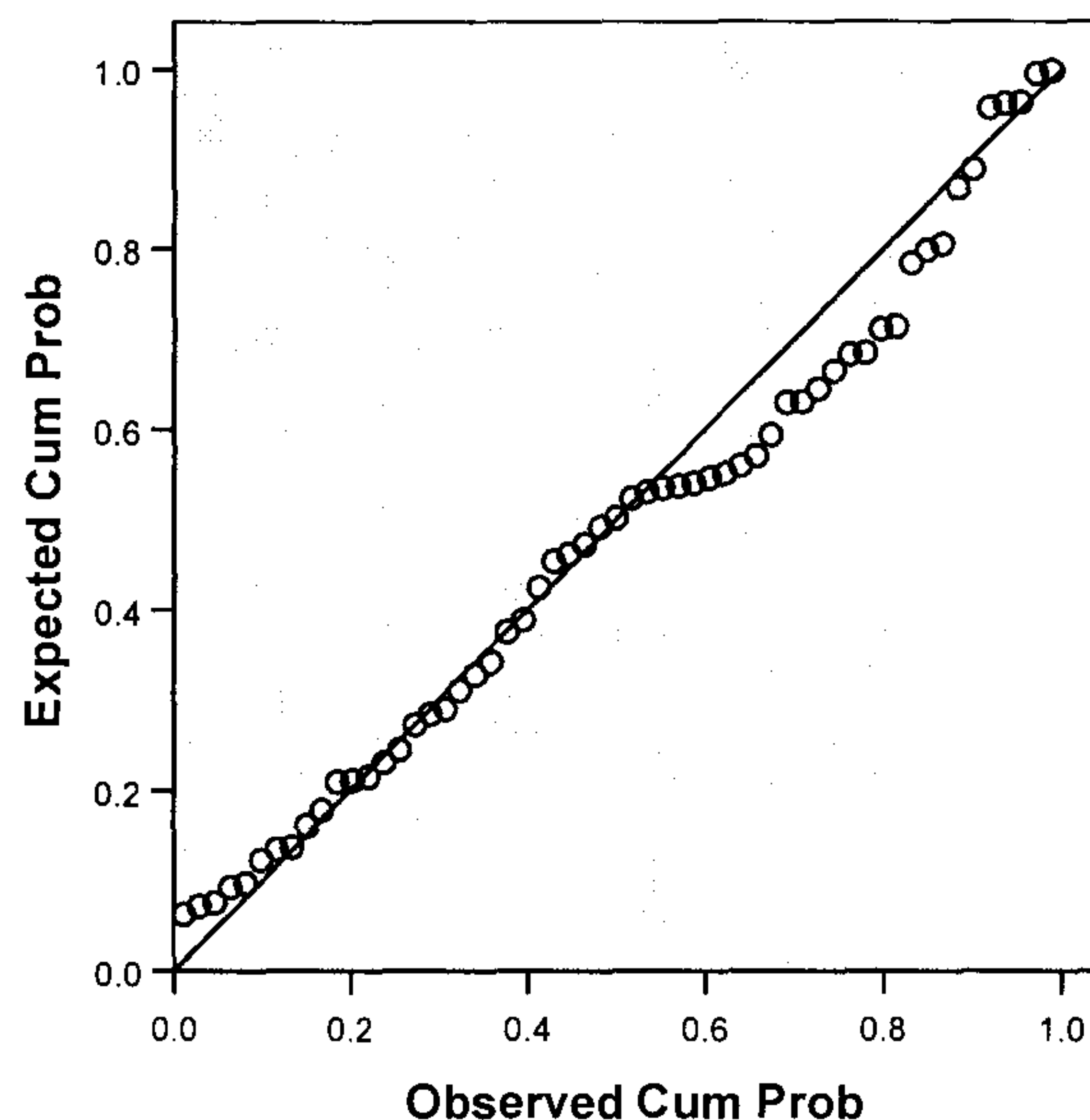


Figure 7.10 P-P plot of the regression standardized residuals for time 2 activity model

Casewise diagnostics were analysed to see whether any cases had undue influence on the model. Only two cases had residuals that did not fall within the range $+2$ or -2 , which is within the acceptable limit of 5% (Field, 2005). All Cook's values were below 1 (the maximum was .58), indicating that no case had an undue influence on the model as a whole. One case had a Mahalanobis value of 24.21, and two variables had a DFBeta value over 1 (activity and treatment control). However, all Cook's values were below 1 (the maximum was .58), indicating that no case had an undue influence on the model as a whole.

This model appears to be reasonably robust with generalisable findings and only two cases that may have influenced the model. The findings do not support the hypotheses as none of the KPBQ variables correlated with time 2 activity, and in the

final regression model only baseline activity was a significant predictor of the outcome variable, with increased baseline activity predicting increased activity at time 2. The final model accounted for 18% of the variance in time 2 activity.

7.4.7.3 Correlation Matrices for time 3 activity

A second longitudinal model was run to examine the variables that predicted variance in time 3 activity. A second correlation matrix was run using baseline variables and time 3 activity levels. Significant positive correlations were found for three variables: total activity, perceived invulnerability, and total beliefs about exercise, whilst significant negative correlations were found for pain and anxiety. The self-efficacy beliefs for exercise variable was also significant but had a highly significant positive correlation with total beliefs about exercise, so was not included because of concerns about multicollinearity. As with the time 2 model, illness expectations and defensive optimism were not significant, but were included to assess their significance in predicting longitudinal activity levels.

7.4.7.4 Regression model for time 3 activity

The significant variables were entered into the model in the following order:

Step 1:	Activity scores
Step 2:	Pain
Step 3:	Perceived invulnerability
	Anxiety
	Total beliefs about exercise scores
Step 4:	Illness expectations
	Defensive optimism

Table 7.14 displays the findings from the regression model (see appendix 6 for the full output). Baseline activity was not a significant predictor of time 3 activity at step 1 ($B = .23, p > .05$), and there was no significant change in variance accounted for when pain was entered at step 2 (R^2 change = .03, $p > .05$). When perceived

invulnerability, anxiety and beliefs about exercise were entered at step 3 the variance accounted for increased significantly (R^2 change = .13, $p < .05$), and when the final two variables were entered at step 4 the increase in variance accounted for was also significant (R^2 change = .10, $p < .05$). In the final model only total activity and illness expectations were significant ($B = .31$, $p < .05$ and $B = -.28$, $p < .05$ respectively), although perceived invulnerability approached significance ($B = .24$, $p = .06$).

ANOVA model 1 = $F(1,55)=2.98$, $p \leq .05$, model 2 = $F(2,54)=2.41$, $p < .05$, model 3 = $F(5,51)=2.76$, $p < .05$ and model 4 = $F(7,49)=3.16$, $p \leq .01$.

Table 7.14 Regression analysis with baseline variables as predictors of time 3 total self-reported activity levels

	Variable	R^2	R^2 change	F change	Df	B^a
Step 1		.05		2.98	1, 55	
	Total activity					.23
Step 2		.08	.03	1.80	1, 54	
	Total activity					.19
	Pain					-.18
Step 3		.21	.13	2.82*	3, 51	
	Total activity					.17
	Pain					-.08
	Perceived invulnerability					.23
	Anxiety					-.08
	Total exercise beliefs					.20
Step 4		.31	.10	3.50*	2, 49	
	Total activity					.31*
	Pain					-.14
	Perceived invulnerability					.24
	Anxiety					-.10
	Total exercise beliefs					.14
	Illness expectations					-.28*
	Defensive optimism					.24

* $p \leq .05$, ^aStandardized regression coefficients are based on the final regression equation

The Durbin-Watson value of 2.06 fulfilled the assumption of independence of errors.

When the collinearity statistics were checked, tolerance scores all exceeded .2 and the

average VIF value was 1.23, indicating no collinearity. However, the eigenvalues for variables 7 and 8 were small and condition index values were large. The variance proportions did not load heavily onto separate variables so there may have been some collinearity.

Scatterplots of standardized predicted residuals against standardized residuals and studentized residuals were produced to check for homoscedasticity. The points were randomly distributed around zero, indicating that the assumption of homoscedasticity was not violated. A histogram and p-p plot were also produced to check for normal distribution of residuals (see figures 7.11 and 7.12). Because the p-p plot showed a slightly unusual distribution a K-S statistic was produced. The K-S value was .09 ($p > .05$), indicating that the findings were generalisable.

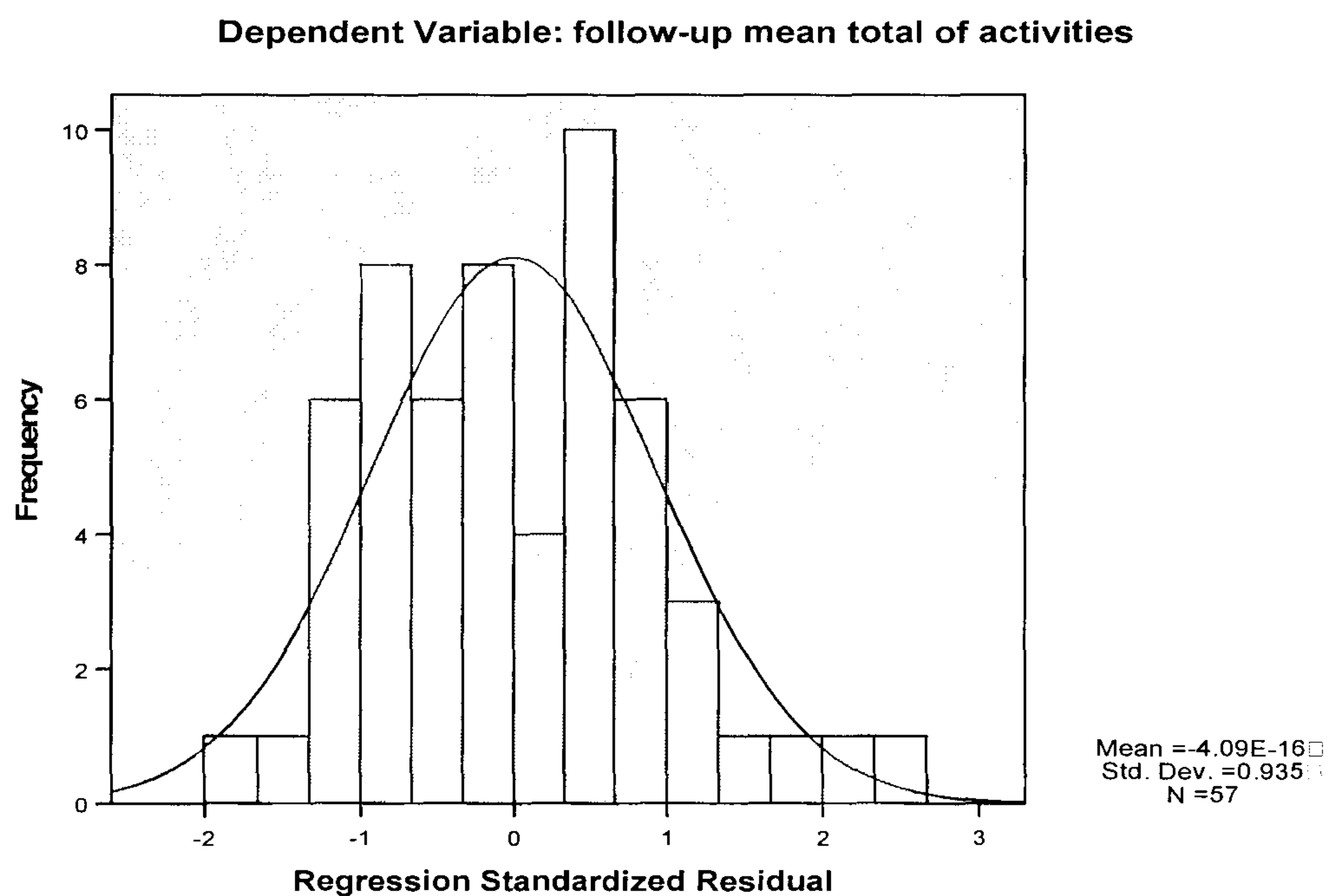


Figure 7.11 Histogram of the regression standardized residuals for time 3 activity model

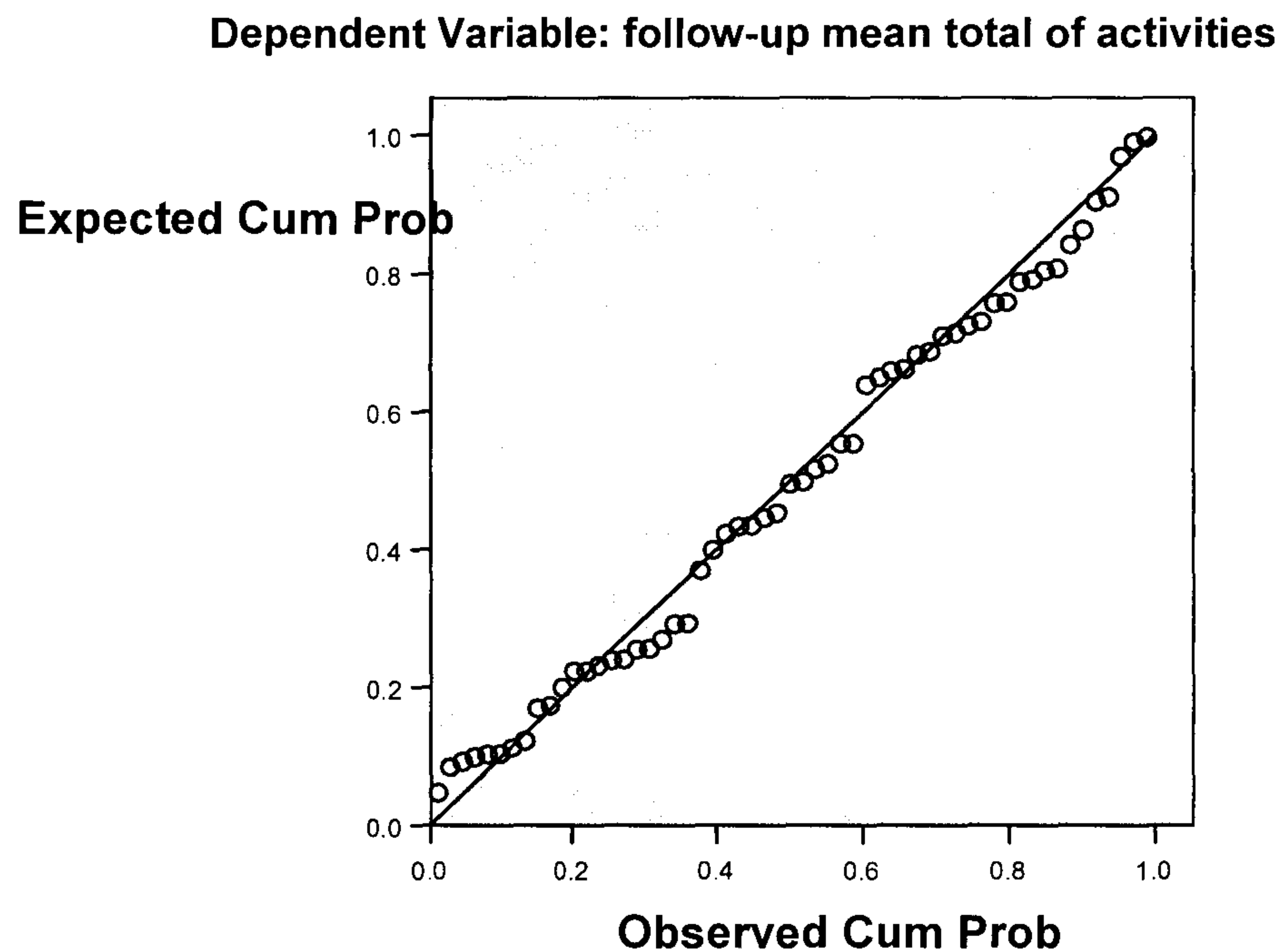


Figure 7.12 P-P plot of the regression standardized residuals for time 3 activity model

The casewise diagnostics indicated that two cases had high Mahalanobis values (approaching 20) and may have exerted undue influence on the model. In addition, the DFBeta values for activity and anxiety variables both exceeded 1. However, no cases had a Cook's distance value over 1 (the highest value was .52).

Assumptions of normality and homoscedasticity were not violated, and despite variance loadings not loading heavily onto distinct factors, the VIF and tolerance values indicate that there were no problems with multicollinearity. Some cases may have had undue influence over the predictors, but the Cook's values indicate that there was no influence on the model as a whole.

The findings of the time 3 model partly support the hypothesis; illness expectations were significant predictors of activity and perceived invulnerability approached significance. Increased illness expectations (more positive beliefs about the condition) predicted lower activity than lower illness expectations, which was the opposite finding to the cross-sectional model. Conversely, increased perceived invulnerability (i.e. not expecting to develop the condition) predicted increased time 3 activity. Possible reasons for these findings and their implications are discussed in section 7.6. This model accounted for 31% of variance in time 3 activity.

In summary, both longitudinal models are reasonably robust and accurate, with generalisable findings. There was a difference in the variance in activity accounted for at times 2 and 3 by the baseline expectations variables and the hypotheses are partially supported.

7.5 LONGITUDINAL ANALYSES – CHANGES IN KPBQ VARIABLES

The previous section looked at longitudinal predictors of activity, including illness expectations and other KPBQ variables. However, little is known about the extent to which expectations change as they are usually only measured at baseline. The analyses described in this section address this issue by comparing the KPBQ variables at three different timepoints.

7.5.1 Longitudinal Hypotheses – Differences across time

Illness expectations and current beliefs will differ significantly across timepoints, whilst defensive optimism and perceived invulnerability will not change.

7.5.2 Participants

Fifty seven participants completed questionnaires at all three timepoints and are the same as those described in section 7.4.2.

7.5.3 Measures

The measures used were the same as those described in section 7.2.2.

7.5.4 Data handling

To ensure that data were normally distributed, the means, medians, histograms and skewness and kurtosis statistics were examined for all variables at each time point. Skewness values were converted into z-scores, and any value within two standard deviations (2.58) was acceptable due to the small sample size (Field, 2005). For variables that were above or below two standard deviations, outliers were moved in towards the next value and the z-scores were recalculated. This resulted in all variables being within two standard deviations, indicating normal distributions. Data were then treated as parametric.

7.5.5 Missing data

Missing data were dealt with as described in 7.3.4.

7.5.6 Analysis

Within-participant error bars were produced to explore the data and ANOVAs were then calculated for each KPBQ factor to confirm these findings. Mauchly's test was conducted to check whether the assumption of sphericity was violated. Where significant findings occurred post-hoc tests with Bonferroni corrections were used for pairwise comparisons, as no clear predictions were made about where differences would lie.

7.5.7 Effect Sizes

Effect sizes for significant ANOVA models were calculated to indicate whether significant differences were meaningful. Omega (ω) was used for the overall model as it is considered a more accurate measure than eta (η) (Field, 2005). Cohen suggests the following values for effect sizes; .10 indicates a small effect explaining 1% of the variance, .30 is a medium effect explaining 9% of the variance, and .50 indicating a large effect explaining 25% of the variance (Cohen, 1992).

7.5.8 Results for KPBQ variables

Mauchly's test indicated that the assumption of sphericity was violated for current beliefs and defensive optimism ($\chi^2(2) = 8.38, p < .05$ and $\chi^2(2) = 14.42, p < .05$ respectively). Because the Mauchly's value exceeded .75 for both variables ($\epsilon = .90$ for current beliefs and $\epsilon = .83$ for defensive optimism), the Huynh-Feldt correction was used (Field, 2005).

The error bars suggested that only the current beliefs variable had significant differences between the three timepoints, and the ANOVAs confirmed this. The ANOVA for illness expectations was $F(2,112)=2.08, p > .05$, for defensive optimism $F(1.67, 93.35) = 1.83, p > .05$, and for perceived invulnerability $F(1.67, 93.35) = 1.83, p > .05$.

The ANOVA for current beliefs was significant with a medium effect size, $F(1.67, 93.35) = 20.93, p < .001, \omega = .35$. Post-hoc comparisons showed that participants' baseline views about their knee pain were significantly less positive than at time 2 or

time 3 ($-.62, p < .001$, and $-.71, p < .001$ respectively), but that there was no significant difference between time 2 and time 3 ($-.09, p > .05$) (see figure 7.13).

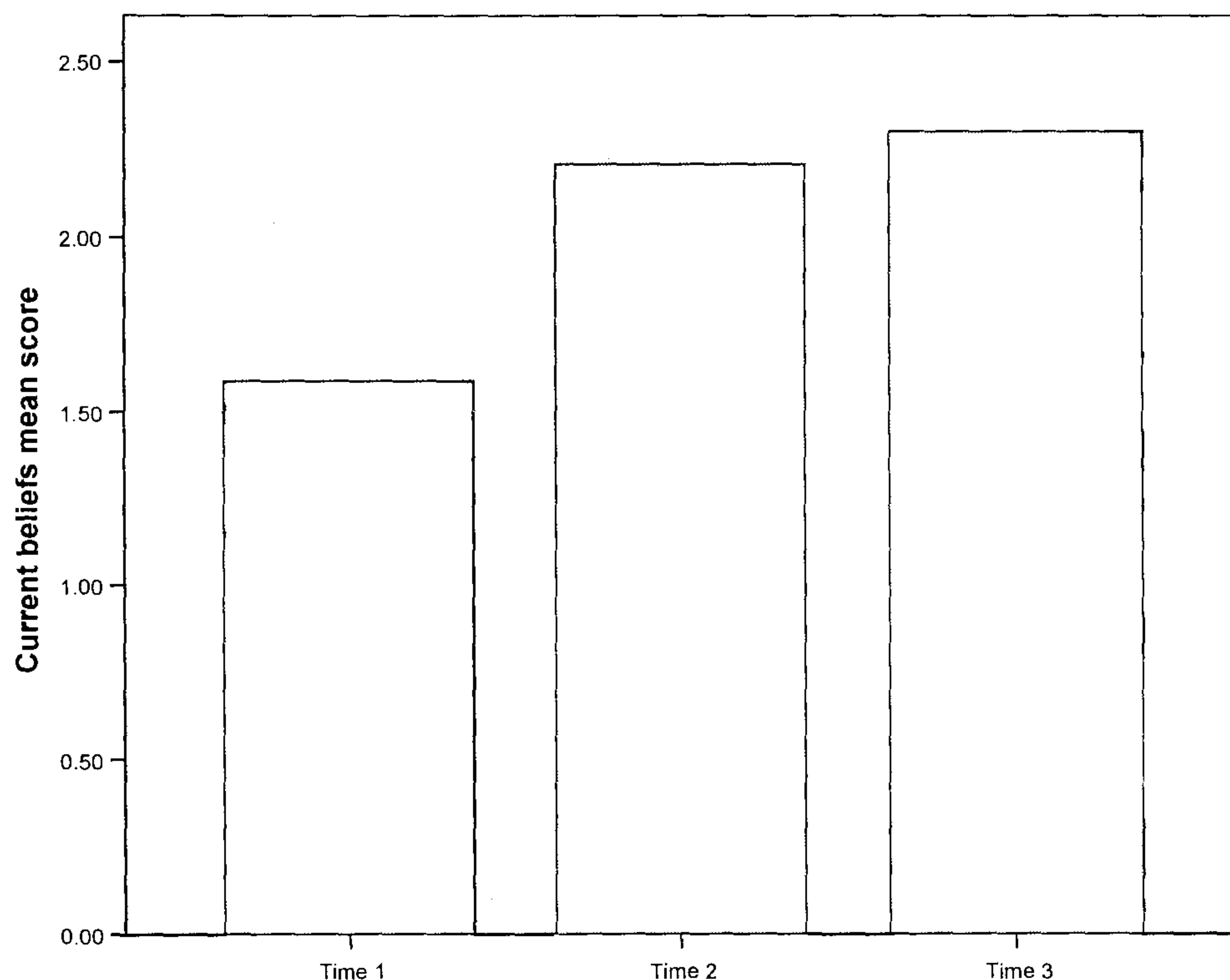


Figure 7.13 Mean scores for current beliefs

7.6 DISCUSSION

A number of analyses were carried out to investigate the role of illness, self-efficacy and outcome expectations in individuals with knee OA, and how stable expectations and knee pain related beliefs are. The main findings of the analyses were as follows:

- In the cross-sectional analyses outcome and self-efficacy expectations did not account for a significant amount of variance in self-reported activity levels, but higher illness expectations scores and lower defensive optimism scores were significantly related to higher levels of self-reported activity.
- In the longitudinal analyses illness expectations and defensive optimism did not predict a significant amount of variance in time 2 activity.

- In the time 3 model, defensive optimism did not predict a significant amount of activity but as illness expectations increased, activity levels decreased.
- Illness expectations, defensive optimism and perceived invulnerability scores did not change over time. However, current beliefs scores were significantly more positive at times 2 and 3 than at baseline.

The findings from the first regression model partially supported the hypothesis that expectations and KPBQ beliefs would explain a significant amount of variance in activity levels; illness expectations and defensive optimism explained a significant amount of variance in exercise behaviour but self-efficacy and outcome expectations did not. The directional hypotheses for the KPBQ factors and activity were partially supported; where participants had more positive expectations about their condition (e.g. not expecting their knee pain to get worse in the future, or to need surgery), they reported higher activity levels, supporting previous findings relating positive expectations to positive outcomes (Mahomed et al., 2002; Flood et al., 1993), whilst those with higher defensive optimism (e.g. feeling optimistic and believing that their knee pain would not have an impact on their future lives) reported less activity.

A second regression model was run, which included non-expectations variables that had correlated with total activity levels. The total WOMAC score was a significant predictor when entered at the first step but became non-significant when the remaining variables were entered. The only significant variables in the model were illness expectations, defensive optimism, and total beliefs about exercise scores, accounting for 25% of variance in activity levels. Whilst this is a significant amount in itself, it only represented a 4% increase over model 1.

The Health Action Process Approach (HAPA) (Schwarzer, 1992a) proposes significant roles for risk, outcome and self-efficacy expectations, and in previous studies self-efficacy has been an important predictor of behaviour, with risk or illness expectations explaining only small amounts of variance (Schwarzer & Fuchs, 1996; Sniehotta et al., 2005). It is therefore surprising that in this study neither outcome nor self-efficacy expectations were related to baseline activity. Because the participants in this study had a chronic physical condition that they may have felt would affect their ability to exercise, illness expectations may have been more influential in determining activity levels than self-efficacy for exercise or outcome expectations. In addition, generalised optimism is not often included as a predictor of behaviour, and so these generalised expectancies may play a greater role than previously anticipated.

How expectations were measured may also be partly responsible for these findings; participants were asked to rate four items specifically related to illness expectations and two to general optimism. This may have provided a clearer indication of their expectations than in previous studies. More detailed measurement of illness expectations in previous studies may have revealed a more significant role for them, accounting for more variance in health-related models.

Illness expectations were positively related to self-reported activity and suggest that if individuals with knee pain believe their condition will cause them major problems or that they will require surgery, they may feel the need to protect the knee by reducing activity, or feel less able to do activities than those with more positive expectations. Conversely, believing that the knee pain will have little impact on their lives in the future was associated with less activity, supporting previous work on students' perceived risk of developing coronary heart disease (Davidson & Prkachin, 1997). The

findings also suggest that general optimism is different to the more specific illness expectations and support previous work (Geers, 2000; Carver et al., 2005), lending weight to the argument that they should be measured separately.

A major limitation with the cross-sectional analyses is that the direction of causality between illness expectations and activity or defensive optimism and activity could not be determined. To address this issue longitudinal data on knee pain beliefs and self-reported activity levels were collected at baseline, two months and eight months. There was partial support for the hypotheses. At time 2, the only significant predictor of activity was baseline activity; none of the psychosocial variables were significant. At time 3 only the illness expectations and baseline activity variables were significant predictors of activity. However, the relationship was in the opposite direction to in the cross-sectional models; as illness expectation scores increased, activity levels decreased.

The reasons for this negative relationship and why the findings were significant at time 3 but not 2 are unclear. Previous work has generally found a positive relationship between expectations and outcome (e.g. Mahomed et al., 2002; Flood et al., 1993; Orbell et al., 1998), as did the cross-sectional model. The gap of approximately eight months between baseline and time 3 may have given participants time to assess whether their condition was improving. If they perceived it was not, this may have led to reductions in activity levels. These findings highlight the usefulness of conducting longitudinal analyses as they provide a clearer picture of the relationship between two variables compared to cross-sectional analyses.

The longitudinal data also enabled analysis of the stability of the KPBQ factors.

Significant differences were seen between baseline and times 2 and 3 scores for current beliefs, but none of the other KPBQ variables showed significant differences between the timepoints. Current beliefs increased significantly (i.e. became more positive) and this sustained increase merits further investigation to determine whether it has any long-term effects on psychological outcomes or behaviour and how long the effect lasts. The reason for the increase in current beliefs scores may have been due to some participants receiving an intervention – a substantial increase in their current beliefs may have caused this difference, even if there was no change for those in the control arm. The findings partially supported the hypotheses as defensive optimism and perceived invulnerability did not change. However, neither did illness expectations and this lack of change may be due to the condition remaining stable therefore there was little incongruent information to prompt a revision of illness expectations.

The findings of this study have implications for the KPBQ measure; the perceived invulnerability factor consisted of only one item, and was retained to allow exploratory analyses. However, although it approached significance in the time 3 regression model it was not a significant predictor in either of the cross-sectional models or the time 2 model. Removing the perceived invulnerability factor would mean that the 10-item KPBQ becomes a measure of only present and future beliefs of knee pain.

Future work could tease out the different effects of the illness expectations and defensive optimism variables, and the relationship between them, how they interact, and how independent of each other they actually are. In an applied setting it would be necessary to clarify whether illness expectations have positive or negative effects on outcomes and behaviour, and how beneficial beliefs can be developed and maintained. Work could be extended to look at the influence of these beliefs in other chronic

musculoskeletal conditions, the way in which these expectations are measured and outcomes. This would provide more detailed information about the influence of different types of expectations on outcomes.

Whilst illness expectations explained significant amounts of variance in activity at time 3, they were not significant predictors of activity at time 2. One reason may be that the relationship was moderated by another variable. Previous work has found moderated relationships between affect and intervention in myocardial infarction (Cameron et al., 2005), expectations of benefit and interventions in chronic low back pain (Kaluokalani et al., 2001), and past behaviour and perceived behavioural control in exercise behaviour (Norman et al., 2000). To examine this possibility future work could utilise moderator analyses to see whether significant interactions between illness expectations and other variables are occurring. Pilot work using the longitudinal data looked at interaction analyses between baseline activity and illness expectations on time 2 activity. The interaction was significant; participants with high baseline activity and less positive illness expectations, and low baseline activity and more positive illness expectations had higher levels of post-intervention activity than the low expectations and low activity, or high expectations and high baseline activity groups. Participants with high expectations may have been more receptive to information on self-management and increasing activity than those with more negative beliefs.

The findings support the inclusion of past behaviour in analyses (Milne & Orbell, 2000; Norman et al., 2000; McAuley, 1992) and illustrate the complex way in which data interact. They also suggest that an intervention may be most effective if targeted at individuals who report low levels of activity and high illness expectations. The implications of the moderator analyses are that in studies that seek to change behaviour

through information and guidance it is important not to assume that participants are a homogenous group and to take into account the influence of existing beliefs and behaviours. In a study of chronic knee pain patients, problem- and emotion-focused copers were matched to appropriate interventions and outcomes compared with a mixed (i.e. unmatched) group (Fry & Wong, 1991). Whilst all groups showed significant improvements in pain, anxiety, satisfaction and adjustment, matched interventions had greater improvements than the control group. Similarly, a RCT that tailored an intervention for myocardial infarction to patients' illness beliefs produced beneficial outcomes, including faster return to work, compared to the control group (Petrie et al., 2002).

There is an increasing amount of research showing the importance of exercise in the management of knee pain (Thomas et al., 2002; van Baar et al., 1999; Fransen et al., 2002; Hurley et al., 2007), but interventions are expensive, so making them as effective and cost-effective as possible is important. If illness expectations and defensive optimism can be used to predict an individual's activity levels, eliciting these beliefs before patients start an exercise regimen may indicate participants who require a more focused intervention. Further work is required with a larger sample to further understand the extent to which beliefs *do* predict different levels of activity to give a clearer picture of how influential they are, i.e. how much variance they account for.

Because interaction analyses require a large sample size (Wahlsten, 1991), this would need to be replicated with more participants to confirm the findings, but suggest it is possible that at different levels of expectations, different patterns of response to the intervention may emerge. Examining this in more detail can provide an insight into interactions between variables that are not seen when only differences in, for example,

randomisation groups are examined. There are currently few examples in health psychology of intervention studies that use interaction analyses (Cameron et al., 2005; Kalauokalani et al., 2001; Norman et al., 2000), which is surprising considering the complexity of interventions employed and the wide range of outcome measures used. Analyses using an adequate sample size will extend knowledge about how variables interact and which participants benefit from specific types of treatment, to improve the effectiveness of potentially expensive and time-consuming interventions. In addition, because such a study would be powered to detect moderate or small effects other patterns may be revealed.

The findings from the analyses should be interpreted with a degree of caution. Whilst the regression models were relatively robust and sufficiently powered to detect a moderate to large effect where one existed, there may be issues in generalising findings to the wider population; the Kolmogorov-Smirnov statistics for the cross-sectional models were significant indicating that the sample deviated from the normal distribution. In the second regression model (containing all the variables that correlated significantly with total activity levels), only a quarter of the variance was accounted for and further investigation is required to fully understand what could account for this amount of unexplained variance. In the longitudinal model there appeared to be no problems with deviation from the norm, but it is possible that several cases had a significant influence on the model, which may be due to the limited sample size.

At each visit some of the data were collected at the time of the assessment and some were completed at home. Efforts were made to ensure that the questionnaires taken home were completed as soon as possible; however this could not be guaranteed, and also resulted in a small amount of missing data. Whilst this was not ideal, it decreased

the burden on patients, which may ultimately have reduced the number of participants withdrawing from the study, and was consistent with how the data in the main study were collected.

The data used in the analyses were pooled from a RCT of rehabilitation for knee pain. Whilst there may have been effects due to the intervention, error bars indicated that there were no significant differences between the three randomisation arms at either time 2 or time 3 for activity levels. Pooling data to give a larger sample allowed the prediction of outcome in a sufficiently powered sample.

Very few studies have looked at expectations as predictors of behaviour, and because expectations are usually only measured at baseline it is unclear how stable they are. This study has provided some insight into these issues and suggests that both specific and generalised expectations are stable over this time period (eight months), and that illness expectations are significant predictors of activity longitudinally. Further work has been suggested to develop this area and to explore in more detail the relationships between KPBQ factors and behaviour, including the use of interaction analyses.

CHAPTER 8: SUMMARY AND CONCLUSIONS

8.1 MAIN FINDINGS

This thesis had several broad aims with respect to looking at patients' OA-related expectations. They were: to examine in-depth the expectations of individuals with knee OA; to systematically review previous studies that looked at the influence of expectations on behaviour following an intervention; to look qualitatively at the longitudinal relationship between changes in the condition and expectations; to develop a questionnaire to measure expectations related to knee OA; to test the questionnaire in a sample of patients with knee OA, to examine the effects of expectations on behaviour and whether expectations and knee pain-related beliefs change over time. The overarching aim of the thesis was to gain a clearer understanding of individuals' OA-related expectations and their role in exercise behaviour. The interlinking studies produced a number of important findings, which are summarised and discussed in the following sections.

8.1.1 Systematic Review

In the systematic review positive expectations were positively related to participants' health-related behaviour following or during an intervention. However, only three studies met the review's selection criteria, none were randomised controlled trials and all suffered from methodological problems, so their findings and conclusions should be interpreted with caution. As a result of the systematic review, several recommendations for researching and measuring expectations were made; more information is required on measures of expectations, such as how they were developed and their psychometric properties, and the type of expectations under

investigation – it is not always clear whether the focus is on self-efficacy, outcome or illness expectations.

8.1.2 Cross-sectional Qualitative Study

In the cross-sectional qualitative study, several main themes emerged. Current expectations were concerned with function and severity; there were few ideas about available future treatment; participants with positive expectations felt able to control their condition whilst those with more negative future beliefs felt that no cure for their knee pain existed; prior experiences and identifying others with “visible” OA (Kravitz et al., 1996) were important sources of expectations; hopes and expectations were used interchangeably to describe future ideas. Similarly, when OA patients undergoing knee replacement surgery were asked about the future, participants often responded in terms of what they hoped or feared would happen (Woolhead et al., 2003). These findings indicate the need for caution when interpreting results regarding whether hopes or expectations are being measured.

The findings support the use of the concept of possible selves to explore how people view the future and their division into expected, hoped for, and feared selves (Markus & Nurius, 1986), and highlight a potential problem with the majority of possible selves work, which ignores the expected self and instead focuses on hoped for and feared selves (Cross & Markus, 1991; Hooker, 1992; Hooker & Kaus, 1994). In addition, an overlap of themes was seen with the timeline, consequences, control (personal and treatment) components of the Self-Regulatory Model (Leventhal et al., 1980). From a methodological perspective, participants were not always able or willing to reveal expectations, although could often do this retrospectively (Haas, 1999; Woolhead et al., 2003), and the reasons for this are not clear.

8.1.3 Longitudinal Qualitative Study

Participants in the longitudinal qualitative analysis reported little change in symptoms over a period of approximately thirteen months. Where symptom changes occurred in the anticipated direction, no changes were seen in expectations. Where changes in symptoms were at odds with expectations, follow-up expectations changed in the direction of physical changes. In participants who expressed uncertainty about the future at baseline beliefs at follow-up appeared to be influenced by the course of the condition, so where the condition improved, follow-up expectations were positive, and where the condition deteriorated follow-up expectations were more negative.

Positive changes in expectations were expressed where participants had received information on self-management, supporting findings in studies on head and neck cancer (Llewellyn et al., 2005) and cardiac problems (Staniszewska, 1999), suggesting that, across a range of chronic conditions, information is taken on board and can influence beliefs. However, it is not clear whether this is dependent upon the type of information provided, how long these changes would last, or which expectations are most amenable to change.

A detailed analysis of the phenomenon of living with OA was also conducted on the longitudinal data. The strongest theme concerned uncertainty (Gannon et al., 2004), which emphasises the need for information provision and has implications for measurement; other themes related to the future, coping and emotional impact. Hopes and fears tended to be expressed more readily than expectations, but participants were able to indicate the probability of these concerns happening.

8.1.4 Development of the KPBQ

The themes which emerged from the cross-sectional interviews were used to develop the Knee Pain Beliefs Questionnaire (KPBQ), a condition-specific questionnaire measuring specific illness expectations, defensive optimism, perceptions of current beliefs, and perceived invulnerability. The KPBQ was shown to have acceptable reliability and validity. Following the questionnaire's use in the quantitative study, the single item forming the perceived invulnerability factor was removed as it did not explain any relationships with activity levels, did not affect activity levels longitudinally, and because it was the only single item factor, inter-item reliability and measurement could not be assessed.

8.1.5 Prospective Examination of the Role of Expectations on Exercise

The outcomes study produced a number of interesting cross-sectional findings. Whilst self-efficacy and outcome expectations have been shown to predict more variance than risk expectations or expectations of a condition (Schwarzer & Fuchs, 1996; Barling & Lehmann, 1999; Sniehotta et al., 2005), illness expectations and defensive optimism (using the KPBQ) accounted for more variance in self-reported activity levels than self-efficacy or outcome beliefs, and had opposite effects. Thus, the more positive the illness beliefs, the higher the activity level, but with higher defensive optimism scores less activity was reported.

Longitudinal regression analyses were employed to examine the predictive power of baseline expectations (and knee pain-related beliefs) two and eight months later. No expectations or beliefs variables were significant predictors of time 2 activity.

However, illness expectations were significant predictors of activity at time 3; as

illness expectations became more positive, self-reported activity decreased. This is contrary to previous work on expectations; more positive expectations generally predict a positive outcome (e.g. Alexandre et al., 2002; Mahomed et al., 2002; Orbell et al., 1998). Whilst reasons for this are unclear it is possible that the relationship seen here is due to individuals assessing their condition and where no improvements are seen in the condition exercise decreases., or moderator effects may have occurred (see section 7.6).

The four KPBQ factors were examined to see whether there was any change over time. Changes were only seen for the current beliefs factor and time 2 and time 3 scores were higher (i.e. more positive) than at baseline. This may be due to differences between the timepoints in participants who received the intervention. Illness expectations did not differ across the three timepoints, which may be because there were not enough changes in the condition over time or in an unexpected direction.

8.2 EMPIRICAL, METHODOLOGICAL AND THEORETICAL IMPLICATIONS

8.2.1 Empirical Implications

This thesis expands knowledge about expectations empirically, theoretically and methodologically. Empirically it provides both a fuller understanding of expectations held by patients with knee OA, and their uncertainty about the future and how they should manage their condition. This identified an unmet need for better information provision, including explanations of how medications work. The way that participants spoke about their future beliefs, and the finding that expectations were

not apparent for all aspects of their condition, should be taken into account when measuring expectations. Although researchers may assume that participants are expressing expectations they may instead be referring to their hopes for the future, thereby producing an inaccurate picture of expectations.

Contrary to previous research (Schwarzer & Fuchs, 1996; Barling & Lehmann, 1999; Sniehotta et al., 2005) the illness expectations factor, along with defensive optimism, accounted for more variance in activity levels than self-efficacy and outcome expectations. This may have been due to more detailed measurement of illness expectations than in other studies or because these were participants with a chronic condition and so illness expectations may have been more relevant than self-efficacy or outcome beliefs. However, it is important to emphasise that this regression model was cross-sectional, so directions of causality between expectations and levels of activity cannot be assumed.

The finding that positive illness expectations had different effects to being defensively optimistic makes the case for a more detailed measurement of expectations; it cannot be assumed that expectations refer to one broad concept. The importance of generalised expectations was also highlighted – it is uncommon to see both measured in the same study so little information is available on how specific and generalised expectations differ in their effects or how they interact with each other (Carver et al., 2005).

In the longitudinal study two interesting findings emerged. Illness expectations were not significant at time 2, but were at time 3. The reasons for this are unclear, but may suggest that the influence of these beliefs emerge gradually; the time period between

baseline and time 3 was six months longer than between baseline and time 2, so may have allowed participants time to reflect that their condition was not improving and as a result exercise decreased. An adequately powered RCT would be required to clarify whether there was any difference between the participants in the three arms of this study.

Of the knee pain-related beliefs only current beliefs differed between the timepoints. It is unsurprising as two thirds of the participants received an intervention that aimed to address beliefs about knee pain, and of the four factors it may be expected that this would be the most open to change. Illness expectations did not change, and conflicts with the findings from the qualitative study in chapter 5. However, this may be due to the condition neither changing sufficiently, nor in an unexpected direction in an adequate number of participants.

8.2.2 Theoretical Implications

A number of theoretical implications arise from the findings of this thesis, relating primarily to the Health Action Process Approach (HAPA) (Schwarzer et al., 1992), and the Self-Regulatory Model (Leventhal et al., 1980). Unlike the SRM, the HAPA has no feedback loop to account for the impact of the action upon the motivational stage for subsequent behaviour. This loop may be implicit, but without it the assumption is that expectations are static or unchangeable, and it is currently not clear whether this is the case. This assumption is also seen in the TPB, where there is no allowance for reciprocal causation (e.g. intention changes are not assumed to produce attitude changes) (Sutton, 2002). Further exploration is required to determine how malleable expectations are and whether they change following new information,

to clarify whether a feedback loop is necessary that would make the model more dynamic.

The SRM (Leventhal et al., 1980) focuses on how individuals respond to a specific health threat or stimuli, both cognitively and emotionally, and incorporates a feedback loop. However, it does not allow for the role of an individual's generalised expectations (optimism or pessimism). There is some evidence from the cross-sectional and longitudinal regression models (and from Carver et al., 2005) that generalised and specific expectations are acting independently (sections 7.3.8.1 and 7.4.7), and a case for extending the model or making a distinct role for generalised expectancies can be made. This may explain more of the variance in behaviours and outcomes. Defensive optimism was not significant in the longitudinal regression analyses, but approached significance at time 3 ($p = .07$) so in a larger sample may have a significant effect. In addition defensive optimism appeared to operate in the opposite direction to illness expectations, i.e. as defensive optimism increased, so did activity, suggesting that the KPBQ does tap into distinct constructs. These expectations may influence an individual's specific representations and so, in the model, could be positioned between the detection of a health threat and cognitive and emotional representations.

A problem with social cognition models is that the emphasis is placed upon cognitions at the expense of emotions. This is addressed by the SRM (Leventhal et al., 1980) through its use of dual processing for cognitions and emotions, and is acknowledged in the IPQ-R with the emotional representations factor (Moss-Morris et al., 2002). The way in which participants in the qualitative studies talked about hopes (sections 4.4 and 5.3.2.2) strongly suggests that they are an important part of

how patients see their condition, and emotions should be explicitly acknowledged in models.

There was tentative support for the structure of the motivational side of the HAPA, which separates out self-efficacy, outcome and risk expectations (Schwarzer, 1992a), but not necessarily the relative importance placed on the different expectations in empirical research on healthy adults (Schwarzer & Fuchs, 1996). Using a measure with more items on illness expectations or looking at a population with a chronic condition (as opposed to healthy adults) may explain differences in the findings. Alternatively it may be because assumptions were derived from a regression model of pooled baseline data.

8.2.3 Methodological Implications

Methodological aspects of expectations research were developed through the construction and testing of a patient driven, psychometrically sound questionnaire that measures distinct facets of expectations (specific – illness expectations, general – defensive optimism) as well as current beliefs about knee pain. Expectations were measured longitudinally to enable both the examination of their influence on behaviour and whether expectations changed over an eight month period, acknowledging the possibility that expectations may be malleable and could be modified in the light of new information.

The empirical findings also have methodological implications for measurement. The systematic review identified a reliance upon a small number of items, which would result in data lacking in sensitivity, and a lack of detailed information regarding which expectations were measured. This makes drawing conclusions from different

studies difficult and emphasises the need to be more explicit about whether self-efficacy, outcome or illness expectations are being tested. The findings from the regression models also open up the possibility of measuring both general and specific expectations to improve understanding of the different influences of expectations and the process of decision-making and behaviour. In a previous study, generalised optimism was a stronger predictor of psychosocial adjustment to breast cancer than the specific expectation (confidence of remaining cancer free) (Carver et al., 2005).

The findings from the thesis suggest that equal importance should be placed on illness, outcome and self-efficacy expectations and this should be reflected in the number of questionnaire items dedicated to each type of expectation. Previous studies have used a disproportionately greater number of items for outcome and self-efficacy expectations compared to illness expectations (Flood et al., 1993; Schwarzer & Fuchs, 1996). The problems of measuring expectations in terms of the overlap between, and interchangeable use of, hopes and expectations were also highlighted, indicating the need to be clear when constructing questionnaires as to whether the interest is on what participants think or hope will happen (Mancuso et al., 1997; Meng et al., 2006).

Pilot work outlined in section 7.6 described the use of moderator analyses, which revealed interesting patterns in data for subgroups, indicating interactions between expectations and baseline activity levels. Previous studies using moderator analyses also found significant interactions between affect and intervention in myocardial infarction (Cameron et al., 2005), between expectations of benefit and interventions in chronic low back pain (Kalaoukalani et al., 2001), and between past behaviour and perceived behavioural control on exercise behaviour (Norman et al., 2000). These

findings support the use of moderator analyses in future studies, particularly where there appear to be no significant effects in the main analyses.

8.3 STRENGTHS AND LIMITATIONS

The cross-sectional qualitative study revealed overlap with factors in the Self-Regulatory Model that concerned both current and future beliefs (Leventhal et al., 1980), providing support for the IPQ-R as a measure of illness representations in non-surgical OA. In addition, participants spoke about medications in terms of the concerns and necessity constructs of the BMQ (Horne & Weinman, 1999), providing support for the extended illness beliefs and medication beliefs model (Horne & Weinman, 2002). Furthermore, comparison of OA patients' medication beliefs with those of other chronic conditions would be interesting; it could be hypothesised that due to the treatment available to OA patients (which focuses on symptom relief rather than disease modification), their concerns would outweigh necessity beliefs, and would differ from other chronic conditions where treatment may prolong life.

The findings challenge previous work on the relative influence of different types of expectations, where self-efficacy has been seen to be most closely related to outcomes (Schwarzer & Renner, 2000; Sniehotta et al., 2005). In this study activity levels were significantly related to illness expectations and to defensive optimism, but not to outcome or self-efficacy expectations. This may have been due to the more detailed way of measuring illness expectations than previously used, and separating out illness expectations and defensive optimism; these factors had opposing effects and so may explain why, if measured together, their effects may be disguised.

However, further work is necessary as findings may differ in a larger sample.

There are limitations of the thesis that should be considered when interpreting the findings. The participants were from a RCT and had been randomised to one of three groups, but for these analyses their data were pooled. Whilst some of the findings may have been attributable to this, error bars indicated that there were no significant differences between the groups on activity scores for either time 2 or time 3.

The participants in the studies were from a small geographical population (South London), which may limit the generalisability to a rural population. However, most trials, unless they are multi-centred, recruit participants from a limited area and so this is a criticism that can be levelled at many studies. In addition, this group were ethnically diverse and recruited from a number of GP surgeries, which would increase variability. A more pressing issue is the generalisability of findings from studies recruiting patients who volunteer knowing they may receive a particular intervention, in this case exercise. Although there was a range of activity levels across the participants, from sedentary to very active, participants may have been predisposed to exercise but unsure about how to start, or whether it was safe to do so (Hendry et al., 2006).

Participants in the quantitative study completed the majority of the questionnaires at their assessment visits, but took the KPBQ, IPQ-R and activity measure home to complete. Whilst this was not ideal and resulted in a small amount of lost information, IPQ-R data had been collected this way up to that point, and avoided overloading participants with questionnaires, which may have resulted in more participants withdrawing from the study completely. Collecting the information this way was a pragmatic way of obtaining as much data as possible.

Whilst the KPBQ showed good psychometric properties it is a newly developed measure which requires further testing to ensure that the reliability and validity findings of chapter 6 remain. However, initial findings suggest that it is a satisfactory way of measuring expectations and other knee pain-related beliefs comprehensively and quickly.

Conflicting results were found between the longitudinal qualitative and quantitative studies in terms of changes in expectations following provision of information. In the qualitative study expectations changed after information provision or in line with unexpected symptom changes, whilst in the quantitative study no significant changes were seen except in current beliefs. This difference could be due to only a small number of participants experiencing changes contrary to their expectations, and therefore not being detected in a quantitative sample. Different findings may have occurred between the three RCT groups, or the measure may not have been sensitive enough to detect change.

A limitation of work on individuals' cognitions in general, but specifically in work on expectations, is that through trying to measure these beliefs they may inadvertently be created (Ogden, 2003), especially if participants have 'unformed expectations' (Thompson & Sunol, 1995). One way of addressing this may be through the use of composite analysis (Yardley & Bishop, in press) in which a qualitative approach is taken to examine expectations in depth, then expectations can be measured quantitatively to look at the degree to which they overlap.

8.4 FUTURE WORK

The findings of this thesis have raised a number of interesting areas for further work. As outlined above, the KPBQ is a new measure that requires further testing. Whilst in many ways these participants were very much representative of the population with knee OA, they were undergoing an intervention that was not available to everyone, so scope exists for further work on a cohort of patients receiving standard care. It would be of particular interest to follow individuals over an extended period of time, for example two years, to look at expectations' interactions with other variables and may also help to explain why, for example, the relationship between illness expectations and activity was not significant at time 2 but significant at time 3. This would require quite a large cohort and the identification of the main variables that could affect outcome, to explain as much variance as possible.

From the qualitative studies participants identified others with OA as their main source of information about the course of the condition, so exploring the development of expectations at the onset of knee pain may be an important area for future work. There are obvious problems with designing such a study, such as identifying participants as they are unlikely to consult their GP, and the possibility of 'medicalising' individuals unnecessarily. However, it would provide more detailed information on how expectations develop, particularly in terms of their source, and how these beliefs affect outcome early on in the condition. This type of study would benefit from the use of composite analysis (Yardley & Bishop, in press); qualitative methodology could explore participants' views in detail, whilst quantitative methods could model the different influences on expectations. If expectations do come mainly from observing others and from past experience as the qualitative interviews suggest, more input may be required from healthcare professionals and arthritis charities to try

and reach patients. It also suggests a possible role for peer educators to inform individuals about self-management.

Exercise has important beneficial effects in OA including maintaining muscle strength and function (Fransen et al., 2002; Thomas et al., 2002; Hurley et al., 2007), and the studies described in chapter 7 found evidence of a link between illness expectations and self-reported activity levels both cross-sectionally and longitudinally, and between defensive optimism and self-reported activity levels cross-sectionally. The findings suggest that expectations may be an important factor in increasing exercise levels, so extending the current study using a larger sample and using interaction analyses to further explore the relationship between variables, would clarify the relationship between the specific and general expectations and exercise behaviour. Appropriate interventions incorporating expectations could then be designed to address the different needs and beliefs of patients (as identified by the KPBQ) (Petrie et al., 2002), and further work conducted to test their effectiveness.

Generalised expectations were important in the cross-sectional studies described in chapter 7, and section 8.2.2 describes an extended version of the Self-Regulatory Model (Leventhal et al., 1980) that incorporates dispositional or generalised expectancies. The feasibility of this model could be tested with a large cohort of OA patients using the IPQ-R, the KPBQ and a well-validated measure of optimism and pessimism such as the LOT-R (Scheier et al., 1994). This would serve two purposes: the extent of the overlap between the KPBQ and specific (IPQ-R) and generalised expectations (LOT-R) could be examined, and would give more information on the significant correlations found between expectations-related IPQ-R factors and illness expectations in section 7.3.7.1; the use of a large sample would enable a more

detailed analysis using methods such as structural equation modelling to predict behavioural and psychosocial outcomes.

In the qualitative interviews participants used hopes and expectations interchangeably, and spoke more readily about hopes than expectations (section 4.5). Further work is required that measures hopes and expectations distinctly and accurately to understand more clearly the relative importance of each construct and the roles they play in outcomes and behaviour. In a previous study different factors related to hopes and expectations were identified by participants (one group identified hopes, another expectations) (Frowick et al., 1986), so a study that measures hopes and expectations separately in the same participants can help establish the degree to which they overlap and test their relative influences on outcomes. This would provide more information on how similar these constructs are, and the validity of studies that use them interchangeably. It would also go some way to explaining how patients use these terms when referring to their condition.

Suggestions are made in this thesis on how to distinguish between expectations and hopes qualitatively (with an initial emphasis on wanting to know about what they would *like* to happen, then what they *think* will happen) (section 4.5), but it is less clear how this could be achieved quantitatively. In particular, issues around “contamination” of cognitions and affect need to be considered and randomising the order of questionnaires could be used to avoid order effects.

In addition to the issue of hopes, the role that uncertainty plays in outcomes may also be important. Future work could examine how “uncertain” individuals differ to those with strongly positive or negative expectations. This could be done by trichotomising

responses (positive, negative and uncertain), then examining differences on a range of outcomes. However, because most expectations scales (including the KPBQ) produce summed scores, sensitivity would be lost in the summing, so examination of individual items may be more informative.

During the qualitative interviews expectations appeared to change in response to new information (section 5.3.1), and participants reported that at onset they were more concerned about pain, but at the time of interviews expectations were related to function (sections 4.4.1 and 4.4.2). A longitudinal, quantitative study is required to ensure this is not an artefact of biased recall, but if supported it would strongly suggest that expectations are malleable so can be modified, and that healthcare professionals should recognise that participants' needs and priorities change over the course of the condition.

Whilst this thesis focused on patient expectations, examining healthcare professionals' perceptions of patient priorities is an important avenue to explore for two main reasons: (1) what patients want and what they prioritise may change over time therefore their treatment needs will change; (2) priorities and needs may be different to what healthcare professionals think patients want (Memel et al., 2000) and may result in patient dissatisfaction with treatment.

8.5 CLINICAL APPLICATIONS

Several clinical applications emerged from the thesis' findings, mainly relating to moderating beliefs and tailoring interventions. Because the KPBQ demonstrated reliability and validity, it can be used as a screening tool for patients with newly diagnosed OA to elicit their expectations. Completion of the KPBQ at the initial

consultation would enable identification of individuals' beliefs, including ones that are incongruent with their current condition.

Once identified, these potentially problematic beliefs may be amenable to modification through discussion with healthcare professionals and relevant information provision. This would use information on expectations to tailor the intervention in a similar way to an intervention with first-time myocardial infarction patients which used the IPQ (Petrie et al., 2002). For example, if an individual has low scores on the illness expectations factor, reasons for this could be discussed, information provided and alternative ways of viewing the condition suggested.

At present it is not clear to what extent expectations can be modified and the effect that these modifications have on behaviour. Further work would be required to explore this, and whether a circular relationship exists, i.e. how much expectations change behaviour and whether the resulting behavioural changes affect subsequent expectations.

The KPBQ could also be used to identify specific groups of expectations. The moderator analyses outlined in chapter 7 indicated that participants with low baseline activity differed in time 2 activity depending on whether the expectations they held were negative or positive. Because of these differences, it would make intuitive sense to target different interventions at individuals with specific expectations. In a study on chronic pain, those receiving coping interventions that matched their preferred coping styles (i.e. emotion- or problem-focused) had better outcomes than those receiving a mixed intervention (Fry & Wong, 1991). Further work would be needed

to clearly determine the different requirements for the distinct groups, but would enable the development of interventions that match individuals' differing needs.

8.6 CONCLUSION

In conclusion, illness expectations were found to account for more variance in behaviour than self-efficacy or outcome expectations and should be measured comprehensively and included in models attempting to account for variation in behaviour. It is possible that expectations are malleable, therefore models which include expectations could incorporate a feedback loop to allow for the possibility of changes occurring. Specific and generalised expectations appeared to work independently and have different effects on exercise behaviour, so measurement of both may account for more variance in behaviour. Hopes and expectations were used interchangeably and more work is needed to separate these concepts out to improve understanding of their influences, to fully appreciate patients' needs and to improve measurement of expectations.

Illness expectations were found to explain more variance in behaviour than clinical variables such as pain, and more established psychosocial variables such as anxiety and depression. The findings support the use of expectations in future studies to examine variance in behaviour. This would include large studies with more complex analyses to clarify whether expectations interact with other variables such as prior behaviour to predict outcome.

It is anticipated that the findings of this thesis and the suggested future work will contribute to a clearer, theoretically based understanding of the role of expectations

on psychosocial adjustment and behaviour in osteoarthritis of the knee. This could then lead to the development of effective interventions and improved patient outcomes.

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APPENDIX 1: ETHICS FORMS AND PATIENT INFORMATION SHEETS

24 October 2000

Professor David L Scott
Consultant Rheumatologist
Rheumatology Department
KCH (Dulwich)



King's Healthcare NHS Trust

King's College Hospital
Denmark Hill, London SE5 9RS

Telephone: 020 7737 4000
Facsimile: 020 7346 3445

Direct telephone line

Dear Professor Scott

Re: LREC No. 00-209
How do expectations influence adherence to treatment in osteoarthritis?

Thank you for your letter of 5 October 2000 enclosing the amended patient information sheets for this study. These are now very satisfactory and I am pleased to confirm that approval has been given on ethical grounds. Please note that approval is subject to the following conditions:

- the project must start within 2 years of the date of approval, otherwise the study must be resubmitted
- any significant changes to the study must not be implemented without the appropriate research ethics committee/chairman's approval
- all serious/unexpected adverse events should be promptly reported to the committee
- a progress report **must** be submitted to the committee on a yearly basis, and a final report on completion of the research


I should be grateful if you would quote **00-209** in any future correspondence.

I understand that you have already discussed Trust approval for this protocol with Dr Mark Lewis, Director of R&D. You will also be contacted at a later stage by Dr Annie Atherton, Research Manager at King's, to discuss any 'research' and 'service support' costs that may arise from this study.

Please note that the King's Research Ethics Committee is compliant with ICH GCP guidelines.

Yours sincerely,



 **Professor Edward R Howard**
Chair, Research Ethics Committee
King's College Hospital

cc. Dr Mark Lewis - Director of R&D, KCH
Dr Annie Atherton - Research Manager, KCH

Contact: Victoria Parr, Research Ethics Co-ordinator
Tel: 020 7346 3923
Fax: 020 7346 3706
E-mail: Victoria.Parr@kingshc.nhs.uk

Patient Information Sheet

Looking At Individual Experiences of Arthritis

We would like to invite you to take part in this research study about the effect that your arthritis has on your daily life. Before you can decide whether to take part it is important for you to understand what the study will involve. Please take time to read the following information and discuss it with your friends and family if you wish. If there is anything that is not clear or if you would like more information, please do not hesitate to contact us.

What this project is about

Osteoarthritis (OA) is the most common form of arthritis in the UK and affects between 15-30% of people over the age of 50. Because it is a chronic illness and can affect many areas of your life, we are interested in your thoughts and opinions about it, and how these change over time.

Why you have been chosen

We are interviewing approximately 20 people from GP practices in South London and your practice has agreed to take part. You have been selected from the patient records because you have been to see your doctor about problems with your knees in the past.

What taking part would mean for you

This study is **not** a clinical trial. Therefore, you will **not** be asked to take any new medication, and all of your current medication will carry on as usual. All we would like to do is find out about your thoughts and opinions about your arthritis, and one of the best ways to do this is through an interview. If you agree to take part in this study, you will be asked to come to your GP practice for an interview with the research assistant (nobody else will be present) which will last approximately 45 minutes.

In the interview you will be asked about different aspects of the arthritis; we want to find out which aspects of your daily life, if any, are affected. Information from the interview will give us a clearer idea about how people who have OA experience their condition. This can then be used to help us to decide on the best ways to measure the effects of OA.

Confidentiality

Confidentiality is an important issue and so the tape-recorded interviews will only be available to the small research team directly involved with the study. The tapes will be kept in a locked cabinet and will be destroyed once the study has finished. Whilst overall results may be published in medical journals, individual responses and results will remain confidential - nobody will be able to identify you.

Your rights

There is no obligation for you to take part in this study, but if you do, you are entitled to withdraw at any time without giving a reason. If you do not wish to take part, or you withdraw, your future care will not be affected in any way. If you wish to take part in the study, please sign and return the consent form attached to this sheet. You will be given a copy of this information sheet and a copy of the consent form to keep.

If you would like more information about any aspect of this study please do not hesitate to contact **Helene Mitchell** on **020 7848 5786**

THANK YOU VERY MUCH FOR YOUR HELP.

PATIENT CONSENT FORM

LOOKING AT INDIVIDUAL EXPERIENCES OF ARTHRITIS

Please read this form and the attached information leaflet carefully

I confirm that I have read and fully understood the information sheet about this study and that any questions I have concerning this research project have been answered to my satisfaction.

I give consent for my interview to be tape-recorded.

I understand that any information I provide will be confidential and that I will not be identified.

I reserve the right to withdraw from this study at any time and understand that this will not affect my health care in any way.

I confirm that I wish to take part in this study.

Patient name (please print): _____

Patient signature: _____

Date: ____/____/____

Name of researcher: _____

Signature: _____

Date: ____/____/____

King's College Hospital

NHS Trust

Helene Mitchell
Study Co-ordinator
Academic Department of Rheumatology
Division of Medicine
GKTSM

King's College Hospital
Denmark Hill
London SE5 9RS

March 7th 2002

Tel: 020 7737 4000
Fax: 020 7346 3445
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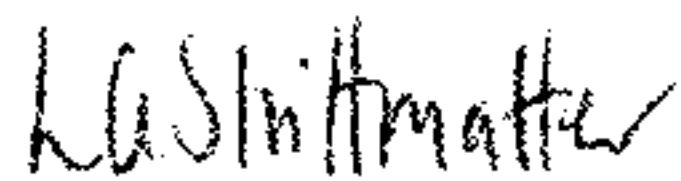
Dear Helene Mitchell

Re.: LREC Protocol No. 00-209
How do expectations influence adherence to treatment in osteoarthritis?

Thank you for your letter received 19.02.02. I am happy to grant approval for your request to extend the study to include OA patients attending the Rheumatology Outpatient's Clinic at Dulwich Hospital (Paxton Ward). Approval is also given for the amended patient information sheet.

I understand that approximately 14 people will be recruited through the outpatients' clinic, and that the interviews will be conducted in the department.

Yours sincerely



Dr D Jewitt
Chairman, Research Ethics Committee
King's College Hospital

P.P.

Contact: Lisa Strittmatter
Tel: 0207 346 3923
Fax: 0207 346 3706
Email: lisa.strittmatter@kingshc.nhs.uk

Copy to Prof Scott

10401 WSC300



King's College Hospital

NHS Trust

Helene Mitchell
Research Associate
Rehabilitation Research Unit
Dulwich Hospital
East Dulwich Grove
London SE22 8PT

King's College Hospital
Denmark Hill
London SE5 9RS

Tel: 020 7737 4000
Fax: 020 7346 3445
www.kingshealth.com

23rd August 2002

Dear Helene Mitchell

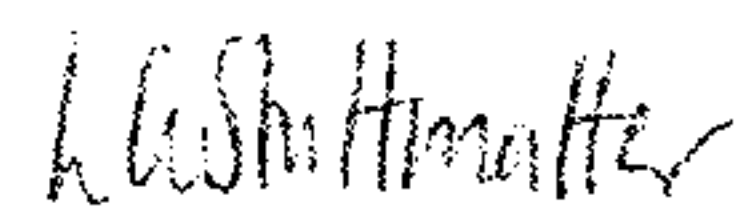
Re.: LREC Protocol No. 00-209
How do expectations influence adherence to treatment in osteoarthritis?

Thank you for your letter dated 21st August 2002. Taking into consideration the difficulties you have experienced recruiting a GP practice to the longitudinal study, I am happy to approve your proposal to re-interview a selection of patients from the cross-sectional study twelve months after the original interview. I would also like to confirm approval for the following documents that were enclosed with your letter:

- Patient invitation letter
- Patient information sheet
- Consent form
- Reply slip

This decision will be reported to the Committee on 18th September and the documents held on file.

Yours sincerely



L.S. **Dr D Jewitt**
Chairman, Research Ethics Committee
King's College Hospital

Contact: Lisa Strittmatter
Tel: 0207 346 3923
Fax: 0207 346 4245
Email: lisa.strittmatter@kingsch.nhs.uk



INVESTOR IN PEOPLE



Helene Mitchell
Rehabilitation Research Unit
King's College Hospital (Dulwich)
East Dulwich Grove
London SE22 8PT
Tel: 020 7346 6095

16th June 2003

Dear

Re: Looking at individual experiences of arthritis and knee pain – follow-up interviews

Last year you took part in an interview with me about your arthritis at your GP surgery. Many thanks for taking part, and I hope you received the report of the study's findings.

I am writing to ask whether you would be interested in taking part in another interview with me, which will look at how your arthritis is now, whether you feel there have been any changes since last year, and if so, how they have affected you. The interview, which will take place at your GP surgery, will last approximately 30-45 minutes.

I have enclosed an information sheet, which explains what the study is about and what taking part would involve for you. If you are interested in taking part you can either return the reply slip in the postage paid envelope, or you can contact me on **020 7346 6095**.

I can assure you that you are under no obligation to take part in the study, and whether or not you decide to take part will in no way affect the care that you receive from your practice or elsewhere.

With best wishes,

Yours sincerely,

Helene Mitchell
Research Associate

PATIENT CONSENT FORM
LOOKING AT INDIVIDUAL EXPERIENCES OF ARTHRITIS
Follow-up study

Please read this form carefully

I confirm that I have read and fully understood the information sheet about this study and that any questions I have concerning this research project have been answered to my satisfaction.

I give consent for my interview to be tape-recorded.

I understand that any information I provide will be confidential and that I will not be identified.

I reserve the right to withdraw from this study at any time and understand that this will not affect my health care in any way.

I confirm that I wish to take part in this study.

Patient name (please print): _____

Patient signature:

Date: ____/____/____

Researcher name (please print): _____

Researcher signature: _____

Date: ____/____

Dr Mike Hurley
Reader in Physiotherapy
Rehabilitation Unit
Dulwich Hospital

King's College Hospital Research Ethics Committee
Research Ethics Office
2nd Floor Hambledon Wing
King's College Hospital
Denmark Hill, London
SE5 9RS

Chair: Dr David Jewitt
Administrator: Sophie Bonser
Direct line: 020 7346 3923
Fax: 020 7346 4245

02 December 2003

Email: Sophie.Bonser@kingsch.nhs.uk
Website: www.corec.org.uk

Dear Dr Hurley

Re: LREC Protocol No. 99-261
Effective and cost-effective rehabilitation for knee pain in a community population

Thank you for your letter dated 03 November 2003 enclosing the following documents relating to a proposed amendment to the above study:

- Sample questionnaire to examine patient expectations with regards to their knee pain

I can see no ethical issues with this proposed additional sub-study and am therefore happy to provide Chairman's approval for this amendment.

This will be recorded in the Minutes of the meeting on 21 January 2003.

Kings College Hospital is compliant with ICH GCP guidelines

Yours sincerely



 **Dr D Jewitt**
Chairman, Research Ethics Committee
King's College Hospital



Patient Information Sheet

Effective and cost-effective management of knee pain

What are we doing?

We are carrying out a study investigating the way knee pain affects people's lives to establish the most effective way of managing patients who have knee pain. You have been contacted because you recently attended your GP surgery complaining of knee pain. We will be recruiting about 550 patients (~20 patients at 25-30 GP surgeries in South East London).

Before you agree to participate in this study, it is important that you understand why we are undertaking this research, and what it will involve. Please take time to read the following information carefully, and discuss it with your friends, family and GP if you wish. If you have any questions, or there is anything that you are unsure of, please do not hesitate to contact us. You are under no obligation to participate in this study, so please take your time to decide whether you want to take part.

Having read the information if you choose to take part, you will be asked to sign a consent form, confirming your willingness to participate. ***It is important for you to understand that you are free to refuse to participate on the trial without affecting your future care. If you do agree to participate, even after you have signed this form you will be free to withdraw from the study at any time without giving a reason.***

Why are we looking at this problem?

Knee pain is very common and can cause disability. The ways in which knee pain is managed might be improved if we understood the condition better, and we could establish what is the best effective and most affordable ways of managing knee pain.

You have been contacted because you recently attended your GP complaining of knee pain and they have agreed to refer patients with knee pain to us for the supervised exercise programme. You will continue to receive all other treatments your GP considers appropriate - ***you will not be denied any treatment, nor will it be delayed, because you are participating on the trial.*** The change in your knee pain and how it affects you will be assessed at regular intervals for 2½ years.

What will I have to do?

Assessment: Patients who agree to participate will be given a mutually convenient time to attend the Rehabilitation Research Unit at Dulwich Hospital. Here, the Principal Investigator, Dr. Mike Hurley, will examine your knees and assess your muscle strength and function. You will also be asked to complete some questionnaires that ask about your use of hospital services and any remedies you use to help your pain, and the ways in which knee pain affects your life. We will arrange for your knees to be x-rayed at the hospital to assess whether your knees have been damaged. (These are standard x-rays and as such carry a very small risk). The assessment will last for approximately 1-

1½ hours. All the information gathered is anonymous and strictly confidential, and will not be made publicly aware.

Following the assessment, you will be contacted by another physiotherapist, who will offer you an appointment to attend the exercise sessions.

Rehabilitation: You will undertake twelve sessions over a six week period, attending twice weekly at a mutually convenient time. These will be held in the Physiotherapy Gym at Dulwich Hospital., and will last for approximately 35 minutes. During this time you will perform a series of exercises to improve your muscle strength and function, and will also receive information on setting goals, planning exercise, relaxation and pain self-management. Although the sessions are not exhausting, you will be expected to work hard, and as such may experience some muscle fatigue after the sessions. Exercises rarely have harmful side-effects, but undertaking any activity that is new to you can sometimes cause discomfort, which disappears within a couple of days. At the end of the programme, you will be encouraged to continue to exercise at home or at organised classes in your area. There is a small risk that exercise may make your knee pain worse, and in cases such as this, the physiotherapist will stop your exercises.

Follow-up: At the end of the 12 sessions, your knee will be re-assessed as before, and you will be asked to complete the questionnaires again. Then 6 months, 1½ and 2½ years later we will contact you and arrange an appointment for you to return to Dulwich Hospital, to repeat the assessments. Therefore you will be involved in the trial for a 2½ year period. Your travel expenses for all appointments will be reimbursed if you present the physiotherapist with a receipt.

The information derived from the study will enable us to decide whether exercise adds to the effective management of your knee pain, and to estimate the costs of this type of treatment. The findings will hopefully contribute to improving the healthcare of patients with knee pain. We would anticipate that the findings of this study will be published in medical journals within 4-5 years.

Because this is medical research, we need to be confident that the results obtained are solely derived from the effects of treatment, and are in no way influenced by the preferences of the patient or researchers involved. Due to this, it is important that you do not discuss your treatment with Dr. Hurley, the physiotherapist that performs the assessment procedures with you, as he must remain unaware of the exercises that you have received.

This study is sponsored by the Arthritis Research Campaign, after its scientific and medical merits were reviewed by five experts. It has also been approved by several local ethics committees.

Thank-you for your time and consideration. We hope this information has enabled you to decide whether you wish to join the study. If you would like to

participate, or have any further questions, please do not hesitate to contact us on the telephone number below.

Ms. Nicki Walsh

Tel: 7346 6358 (24 hour

answerphone)

Senior Physiotherapist

Rehabilitation Research Unit

King's Healthcare (Dulwich),

East Dulwich Grove,

London, SE22 8PT

APPENDIX 2: QUALITATIVE DATA

Interview Schedule

How are things currently?

Past

- When were you first aware of any problems with your knees?
- What happened when you were first diagnosed? (*treatment/feelings*)
- When first aware of problem/diagnosed, what did you think would happen (*both outcome and treatment*)?
- (Can you tell me why you thought that?)

Present/Future

- And how does that compare to how things are now?
- What do you see happening in the future, in terms of the arthritis? (*and why*)
- (How confident are you that that will happen?)

Future Management

- What sort of things do you think you can do? (*both outcome and treatment*)

Current Management

- Can you tell me what sort of things you do to manage the OA at the moment
- If take meds: what do you **think** it will do? What do you **hope** it will do
- If take **no** meds: why? What do you think will happen in the future?

Role of Others

- What do they think you can and can't do?
- What do you think your family and friends think about how it affects you?
- How do you feel about that?

(*Anything interviewee wishes to talk about?*)

Transcription Notations

()	Brief pause, approximately 1 second
(4)	Substantial pause – number in brackets denotes number of seconds
bold text	Emphasis on word
...	Non-relevant material omitted by author
[text]	Explanatory text added by author
[<i>text</i>]	Contextual notes added by author
(text)	Speech not completely clear, best guess by transcriber

I: okay, if you can tell me how your knees are at the moment

P: er, what, right now?

I: yeah, sort of currently, the last couple of weeks

P: well, erm, they do hurt occasionally but they're not the hurt that I can't cope with

I: mm-hmm

P: I get annoyed with myself, especially when I try to get down and I can't get up again [*P laughs*] but then I am nearly eighty years of age so I think to myself well I'm lucky really erm, but as I say it's not something that I can't cope with

I: mm

P: and I don't take pills for that, I put up with it erm () that's about it really er, no I can walk, and I can walk quite long distances so I feel hopefully [*P knocks on the table*] () if they stay like this I won't have any problems

I: mm, and you said that in terms of sort of functioning you, you can't get down but you can walk

P: yes, sometimes I find, well I do find it, it's not sometimes really, I do find it a bit difficult to get down

I: mm-hmm

P: and then get up

I: right

P: and get into the bath or, you know some days I'm alright, some days I'm not

I: mm

P: I suppose it depends on how your body's functioning and how, you know, but I found actually my dog died two years, two months, three months ago er, well she had to be put to sleep with cancer really and I have put in now for a guide dog and I feel that the more walking I do, the better it will be for me

I: mm

P: but at the moment I'm having a few problems with my knees because I'm **not** walking

I: mm

P: and I always used to go out for about an hour, hour and a half's walk

I: yeah

P: and it does make a lot of difference

I: is there

P: really

I: sorry, is there anything else that it causes problems with?

P: what, the arthritis?

I: yes

P: erm ()

I: such as stairs or anything like that

P: well yeah, sometimes you know, when your knees are bad, you're, you know, going up and down stairs is a bit awkward, but not so severe for me

I: mm

P: so I'm lucky really

I: mm

P: but then also, I've got a disabled hand that was smashed, I've got a scar right up there

I: oh yes

P: and **this** () **this** is the problem

I: mm-hmm

P: because I can't, I have to use special knives with special handles

I: mm

P: and I can't pull out plugs on the wall, I have to have those things on them you know, like handles

I: yes

P: but apart from that

I: mm

P: you know, I'm not too bad really

I: yeah, erm, and you said that walking tends to make it a lot better

P: oh, I'm sure it does

I: erm, is there any other thing, anything else you can think of that tends to either make the arthritis better or worse? You mentioned before actually, food as well

P: (2) well yeah, I daren't touch, I **daren't** touch rhubarb and mushrooms

I: mm-hmm

P: for some reason or another they really do you know, go hell for leather and so I don't touch them at all, I **do** have a tomato occasionally, especially when I have, have a salad

I: mm

P: and er, I know when I've had tomatoes but then if I can remember it, I take a tablet before I go to bed! [*both laugh*] but in the mornings () erm, my knees are a bit of a problem

I: right

P: you know, but I feel they shouldn't be really, because you're resting, resting them, all night, aren't you?

I: mm, yeah and

P: you know, it's very difficult to understand this sort of thing really but I've, I have had more problems with that since I haven't been walking so I know that for a fact

I: mm

P: you know, I think the more you walk, you don't have to walk fast

I: no

P: or tear around like a mad thing, if you just go for a nice walk, but you don't feel like going for a walk on your own really, it's a bit boring, isn't it?

I: mm

P: and I certainly wouldn't go up the common on my own () 'cos I was up there the day that girl died

I: oh right

P: got killed () and I wouldn't go up there on my own, although the erm, the wardens are very good, very good up there

I: mm

P: but apart from that I don't know what else to say, really

I: and you mentioned that, for example, if you're gonna have tomatoes you take a tablet

P: oh yes! [*both laugh*] I take, I don't have co-dydramol now

I: right

P: because I don't **need** them, they're strong tablets

I: mm

P: and I don't need them but I do take (2) Panadols

I right

P: so I take a Panadol and hope for the best [*I laughs*] it don't always work! [*P laughs*] it don't always work but there you go

I: do you take those fairly regularly or is it just when you've been
P: no, no, when I, well this is where the doctor and I come to blows
I: mm-hmm
P: because () I tend to, I don't know, I tend to think to myself, I'm gonna have a bad night, so I'll take a tablet
I: mm
P: and then I go off and sleep and I'm alright, sometimes I'm just sitting in the chair and your knees are painful, you know, but erm, not something I can't cope with, whether I, whether it's **me** that can cope with pain or not, just me
I: mm
P: you know, I don't know, but erm, or whether it's not severe enough for me to, it used to be
I: right
P: it used to be before I had this letter from Carol telling me not
I: mm
P: you know, what not to do and what to do but I tend, since I've done all that, I'm quite good [*P knocks on table*] I can cope with the pain
I: yeah
P: because it's not so severe, I was nearly running up the walls with it really, it was so painful, in my arms and my legs they were dreadful
I: mm
P: even though I was walking and when I went as I say, when I spoke to Carol, she was telling me about her mother and what she did
I: mm
P: and I thought that's what I should do
I: mm, and when you talk about pain, what sort of pain is it? That you used to have and maybe that you have now?
P: well, same pain as I have now but a lot stronger
I: mm-hmm
P: a lot stronger and it **used** to affect the **whole** of my body, not just my knees, **all** of it
I: mm
P: it used to go from my oh, from my arms right through my body right down to my, oh, it was dreadful
I: mm
P: and thank god it doesn't go like that now
I: and was that a sharp pain or more of a dull ache, that you tended to get?
P: a dull pain, real pain
I: mm
P: and it was something I couldn't really describe and I couldn't really get rid of, you know? and as I said to try and speak to Dr *** was absolutely hopeless because she just would not listen
I: mm
P: in fact she had her son here a few weeks ago and it was all hello, Mrs *** how are you? And she said, I said to her, I don't care if you can give me a prescription, you can give me the pills but I'm not taking them so it was xxx! [*P laughs*] but, you know, that's like () when you go to a doctor they don't have time to listen, they don't listen half the time to you, if they did listen they'd know what to do, but they don't. I mean I'll give you an instance, now I had a very bad foot, and it's still bad now, I'm still under the hospital with it, when I had that accident, would she listen to me? She wouldn't, she sent me for three x-rays, I said I don't need an x-ray on it, I said there's

something there I said, and it's very, very painful but it's not a break, I know when I've had a break

I: mm

P: I said, oh she said [*tape changed over*] it's rheumatism, I said it's **all** due to that accident when my foot went down the hole, it could be arthritis now

I: mm

P: couldn't it? Only it's not an arthritis pain 'cos it's all round here

I: right

P: all across here and it's as if I've got a strap right across the front of my foot and it's **there** all the time

I: mm

P: and my leg from here down to there occasionally it's very white [*P indicates from just above the ankle to the mid foot*]

I: mm

P: just I mean all that is money wasted, in my eyes

I: mm-hmm

P: because three x-rays and they said there's nothing wrong with the foot, I said there is but it's not a break, I know that () so now she's sent me to physio and the physio can't do anything I: mm

P: and the physiotherapist said she's going to send me back to er, this doctor, er, she said because I don't quite know what's wrong so I said well, I don't want to waste anybody's time, if it's something I've got to cope with

I: mm

P: then just tell me

I: mm

P: and I'll cope with it, I said I'm not an idiot

I: () yeah, and you said that before you started cutting out certain foods

P: mm

I: the pain was sort of driving you up the wall

P: yeah

I: and were you taking the painkillers then?

P: yes I was taking a lot of co-dydramol then

I: right, right

P: and it wasn't affecting me at all

I: mm () how did you feel about the fact that the painkillers didn't seem to be helping, but you were still having

P: well, well that's what she said to me, that's when she said to me well, you must take, that's your fault, you should take two four times a day so I said to her but when I took, started taking two four times a day I was walking around like a zombie

I: mm-hmm

P: I said, and I do not **wish** to walk round like a zombie, I want my brain to work

I: mm

P: I said, as a matter of fact I said when I walked around the park one day to, to go to the station, my neighbour came across to my husband and said am I on some form of drugs? Because I wasn't walking straight

I: yeah

P: now I didn't know I wasn't walking straight and I thought I'm not taking any more

I: mm

P: so er, that's when I started to listen to Carol, she said to me you know, work, go on your food

I: mm-hmm

P: and deal with your food, and if you can deal with that she said, and whatever food you feel brings on the pain of the arthritis leave well alone

I: yes () how did you feel about doing that when she first suggested it?

P: well, she's pretty good is Carol

I: mm

P: and erm, as her mother was in such a mess, she's not one of these people that would say oh you've got to, I tried this, I tried this on mum and, you know

I: mm

P: she talked to me like you're talking to me and said well, if you feel it's worth a try, do it

I: mm

P: but she said I will tell you one thing, she said, I've discovered **many** people it's oranges and rhubarb, it's the acid and yet I can drink lemon, I can **eat** a lemon, and it doesn't affect me at all

I: mm

P: it's the different acids, isn't it?

I: mm

P: so you know, and I thought well it's worth a try and I do love potatoes but I've cut down quite a lot on them

I: mm

P: and touch wood I don't have nearly as much pain now, it annoys me when it comes [*P laughs*] but I don't think I ought to be in pain but there you go

I: were you surprised at all about how dramatic it was? It sounds like it's fairly, it sounds like there's a big difference between how you were and how you are now

P: well, I felt, I felt on top of the world with myself really [*both laugh*], you know, I felt quite chuffed with myself and when I hear people who've got arthritis I tell 'em () I say oh why don't you, you know, deal with your food, it's sometimes it's food, like the acids and that and I don't drink wines or anything like that, I do occasionally if there's a wedding or party or anything like that, or white wine, but I don't drink a lot, not because I'm a teetotaller or anything like that, or () I just don't like all these wines, there's only one or two that I do like

I: mm

P: so I mean that's, that's no problem, but as I say I do love oranges

I: mm

P: but I don't dare touch them

I: no

P: and I do love rhubarb, rhubarb pie

I: mm

P: don't dare touch it, because I did realise, I **even** dug it up from the garden so that I wouldn't touch it! [*both laugh*] and threw it away

I: so you wouldn't be tempted

P: no, when I go shopping I look at these oranges and I think oh, close your eyes, walk away! [*both laugh*] it's terrible really, you know

I: mm

P: and I don't drink orange juice for fear of that

I: mm, yeah

P: but there you go, I mean, you either suffer unnecessarily or you do what's right for your own body, don't you?

I: yeah

P: really, but I do feel sorry for these, some of these kids that my daughter sees that have got (brain) problems and arthritic as well, which is bad really

I: mm

P: but there's not much you can do about that

I: mm, how long is it that you've had problems with your knees?

P: (2) ooh () quite a few years really () on and off they come, it's not continual

I: mm

P: erm () I would say a good ten years

I: right

P: a good ten years

I: do you have any

P: but then I think a lot of, lot of people like **my** age () I think a lot of it was to do with the war and the shelters

I: right

P: the dampness, and riding a bike because your knees always get wet don't they? And you don't bother to dry them [*P laughs*] and I always rode a bike during the war

I: right, that was actually going to be my next question [*both laugh*], do you have any ideas about what caused it?

P: yes, I'm sure that must have been it, and I was, I was an air raid warden so I was in and out of shelters you know all the time and they **were** damp erm, you couldn't expect them to be anything else really

I: no

P: I mean it wasn't that we slept in the shelters, 'cos we didn't, we had a ground floor flat so we were pretty lucky there, erm, but I **did** go in and out of shelters quite a lot and erm, and I'm sure a lot of it, my problem **was** riding the bike and getting wet

I: mm

P: and not drying them, so it's my own fault, isn't it? [*P laughs*]

I: erm, and you said that you've probably had problems on and off for about ten years erm

P: longer than that probably

I: right

P: I'm not absolutely sure

I: that's fine erm () can you remember **why** you came to see the GP about the knees initially?

P: I didn't tell her, because she wouldn't listen anyway

I: right

P: I told Dr Reese

I: mm

P: the old, my old doctor

I: yeah

P: and she said to me if you can put up with the pain now, she said do it

I: mm-hmm

P: Polish doctor she was (Polish lady) because she said later on in life you will definitely need something so it's better that you take it later on in life so that it does you more good, than now

I: right

P: she said because later on in life you'll have to have stronger tablets so she said your best bet, if you can cope with it now, I said oh yeah, I can cope with it, so she said fair enough

I: mm

P: so that's what I did, you know, I listened to her, she was quite good

I: mm

P: and she would listen to xx anyway

I: mm

P: but when you get a doctor that's so arrogant and won't listen it's a bit much

I: mm

P: somebody said to me oh change your doctor but I thought well xx 'cos I don't come up here

I: no

P: and when you're not here very often I don't () I don't need to bother

I: mm

P: buy my own tablets

I: yeah

P: don't bother

I: yeah, and with your old doctor, Doctor Reese erm, when, when she said, you know, later on in life you'll need

P: yes

I: how did you feel about that, or what ideas did you have about how the arthritis would, would be

P: I **trusted her**, I **trusted** that lady a lot

I: mm

P: erm, and I thought well if that's what, she's a doctor

I: mm

P: I'm not a doctor, or a nurse so I **listened** to her and I thought well, she would know that as life goes on, you know, pain gets stronger

I: mm

P: so I just listened to her and done what she said and she said if things get too bad she said come across and see me and I just coped

I: mm, yeah

P: yeah

I: how did you feel about the idea that from what she said the arthritis **would** get worse?

P: I didn't take much notice really, I probably thought at the back of my mind oh it might not [*both laugh*] knowing me! You know, 'cos I'm not one of these thing, people that dwell on things

I: right

P: I suppose really it's because I, well, it's a family trait really, I was born with a very rare eye condition and I've had to cope with life, with **that** life

I: right

P: so you cope with everything, my father was blind, a blind person and he used to say well you've got hands, you've got legs, use them

I: mm

P: you know, don't let this problem get you down, you use whatever you've got

I: mm

P: so (2) you know

I: so you didn't really think about the future

P: I didn't think that it would

I: mm-hmm

P: possibly I didn't believe, you know er, that it was absolutely true, I might have believed or I might not have

I: mm

P: 'cos she used to say to me have you got anything, is there anything wrong, can I help you with anything, I used to come over for my husband's medication and she'd say oh, I used to say to her yeah well I've got a few pains in my knees, you know [*P*

laughs] I suppose it's due to my, to the war effort [*both laugh*] so she used to say oh **maybe**, maybe it is due to the war effort but she said you know, do you want anything for it and I said well I don't really know really, it isn't that bad at the moment and that's when she said you know, it's just as well if you can

I: mm

P: put up with pain now and erm, because later on she said you'll probably, it probably will be worse and you will need some pills

I: mm

P: but she wouldn't **insist**, not like [*P points to the wall*]

I: mm

P: I mean you know your own body don't you? You know, I don't need to be filled, I tell you what I'm, she gave me () antiboiotic a few months ago and I blew up like a balloon, now she knows I, I'm allergic to most of them

I: mm

P: and she said to me, I said I don't really want those, doctor, so she said well, she said this is special for those that are allergic to antibiotics and she said this shouldn't affect you at all () I was in a mess

I: mm

P: and I still am occasionally in a mess because of that because I come out all in red marks and itchiness and it drove me crazy but I won't come up to her because it's pointless, absolutely pointless

I: mm

P: because she won't listen, she will, she will vow and declare that it wasn't the pill anyway but it was

I: mm

P: because I had to leave it off in two days and my daughter put 'em down the loo [*I laughs*] a dreadful mess

I: and

P: oh I tell you another thing

I: mm

P: how long ago was that? This was about eight or nine years ago () I came up here to Dr Bristowe, that's right, and that was when he first put me on co-dydramol, he gave me a pill () and, for arthritis, I can't remember the name of it, but I was terrible, my daughter came in one day, she said what's wrong with you? I said nothing, why? She said, but you're not walking straight, you're not talking straight she said it sounds to me as if you're on a high and I went to go, I went to put my feet on the step and I couldn't find it! [*P laughs*] I could not find that step, anyway, I went upstairs then I came down again, the next day I went, I should have got some meat out of the freezer and I'd forgot so I went round the corner to get some meat, do you know what I did? I walked straight in front of a car (2) I walked straight in front, and fortunately it was a doctor and he knew what I was about to do and I got to across the road and I sat down on the coping because by the time I'd got across the road I realised what I'd done

I: mm

P: and he said to me er, are you on any medication? I said well, yeah but only for arthritis – only for arthritis - I said but only for arthritis so he said er, well I'd take them back to your doctor if I was you he said, let me take you home, so I said no, I can't go home I've got to go round and get some meat! [*both laugh*] get some meat for the children's you know, meal tonight! Anyway, he was very good, but he never gave me his name and, but he did have doctor on the car

I: mm

P: and he took me round to the doctors and brought me home and said now don't forget, he said don't take another one of those pills

I: mm

P: and I did show him those pills and he did say don't take, he said they're a trial

I: right

P: so he said throw them away and go, tell your doctor what you've done

I: mm

P: but I didn't get a chance 'cos my daughter did! [*I laughs*] but I don't know what they were, but from then on I was afraid

I: mm

P: I was afraid of taking **anything** else for arthritis

I: mm

P: because it frightened the living daylights out of me, but I **knew** that co-dydramol was like a Panadol and something else but I **really** needed them at that time

I: mm

P: but **not** four times a day

I: yeah

P: I needed them when I felt that I needed them when it was **all** through my body well touch wood I don't get that now, it's wonderful really

I: mm, did that, that **really** bad pain, did it come on gradually or did it seem to come on all of a sudden?

P: no, it came on all of a sudden

I: right

P: I couldn't, I didn't **feel** that I could control that for some reason or another

I: mm

P: and that's when I said to Carol, you know, it really grates me to think that you know, if I could only tell when it came on

I: mm

P: I'd take something and ward it off

I: mm

P: er, but I couldn't because it used to come on so sudden and it used to make me feel so **ill**, you know, and probably because I didn't really know how to cope with it

I: mm

P; but I couldn't cope with that

I: mm

P: but **only** since I've been over to Carol and I decided to do what she said, have I been able to cope with it

I: yeah

P: not my knees, but the rest of

I: mm

P: and I feel, to be honest, on top of the world, because I **know** how to treat myself now without a problem

I: mm, yeah, when () when it was especially bad, did you have sort of, what were your feelings about the future and sort of how

P: I didn't even **think** of the future really, I just thought to myself well Dr Reese is right, she said it would come on bad and

I: mm

P: and I'll have to take the pills, and I was tempted to take two four times a day and then I thought well, when it really got bad I thought well I will have to take them and I took them but then I wasn't **happy** about taking them because I didn't feel with it

I: mm

P: and I er, I know penicillin is a nightmare with me, I daren't touch, I daren't have anything like that and I thought [*P sighs*] () what am I going to do?

I: mm

P: and I thought to myself the only way out or the only (try) is to do what Carol said

I: mm

P: and try it and when I suddenly realised () oh, I'm not taking them, so many pills and I wasn't getting that feeling

I: mm

P: I thought great, I felt great, you know? It's () a wonderful achievement really, because I thought well if I hadn't gone over to see my niece () and if my daughter hadn't gone to erm, Australia and one of the Solomon Islands to open up er, the medical centre

I: mm

P: or to help them, you know

I: yep

P: organise this medical centre () and I poked my nose in and went with her! [*P laughs*] I wouldn't have been like I am today

I: mm

P: would I?

I: no

P: because I mean I write to Carol, I phone Carol, but I don't ask for all these sort of things, she's opened a shop now in Auckland that erm, she gives people advice

I: mm

P: which is good but () you know, I feel quite proud of myself really

I: mm, and do you have any ideas about, the sort of

P: the thing is, interrupting you

I: that's fine

P: would **everybody** be like me? You know, would, would the, what I've done help ever – it wouldn't would it?

I: not really

P: not really, no

I: no

P: because there's all sorts of arthi, arthritis

I: mm

P: problems, isn't there?

I: mm

P: yeah, I didn't think it would be, but it acted quite well

I: mm, sounds like it

P: for me! [*both laugh*] but I don't **not** have any problems

I: no

P: because I do, but they are not nearly so severe, when it was going all through my body, up here right the way, well, I didn't feel I was gonna cope with it

I: mm

P: so I'm quite chuffed with myself really

I: and how would you say your outlook is now, in terms of the arthritis?

P: well it's not getting, hopefully it's not getting worse

I: mm-hmm

P: but it's really sort of stable, I think at the moment

I: mm

P: but whether it will get worse, I don't know

I: right

P: er, because you don't know what's round the corner, really do you

I: mm

P: erm hope, I'm hoping () I can cope with it as it is and I'm hoping, I **hope** it stays as it is really

I: mm

P: erm, but you don't know do you?

I: no

P: not really () as you get old and crotchety! [*both laugh*] hopefully, hopefully when I get the dog

I: mm

P: erm, I shall, I'm toying with the idea really, my last dog was Suzy I had her for twelve years and she was a sad old thing, say, she was found in a shed and she'd been in a shed for six to eight, about four to six weeks she was nearly dead when they found her actually and erm, she couldn't be put in a home because she was too, she was as nervous, now for instance if I brought her here today, if she was alive and I brought her here today, you couldn't close that door because she'd get into panic stations

I: mm

P: because she was found in a shed

I: mm

P: she was shut in the shed for so long and so **all** my doors were left open but apart from that she was, she was quite good, she was a lovely animal but they, when I went to Moorfields a couple of weeks ago they said to me well get a, have a guide dog but I see so, there are so many animals out there, that really do need a good home

I: mm

P: I'm just wondering whether I **should** have a guide dog or whether I **should** get one of them

I: mm

P: I'm having an argument with myself at the moment [*both laugh*]

I: have one of each and be done with it!

P: pardon

I: have one of each

P: yeah, 'cos you know, some people are so cruel to animals though, really aren't they?

I: mm

P: I mean and these people that had Suzy erm () they were only fined two hundred and fifty pound **each**

I: shocking

P: and banned for keeping a dog for three years, I mean, if you'd have seen her, she was a cross between a chou and a collie

I: mm

P: she was two thirds chou and one third collie, **beautiful**, beautiful coat and everything, she was a lovely, beautiful temperament, and how they could leave her in a shed I don't know

I: yeah

P: because I mean this day and age, years ago, probably you could say well, they didn't want it and that's all there is to it

I: mm

P: but this day and age, there's so many, so many places out there that you can take them if you don't want them and if you don't want them why have it?

I: mm

P: same as children when **they're** left on the doorstep, I mean there's so much, it's evil really but there you go, not much you can do, now **she** had arthritis

I: oh did she?

P: yeah, yeah, she had arthritis in her leg, her back legs and erm, then she went deaf for three years so we had to do sign language! [*P laughs*] but she coped

I: yeah

P: I coped

I: well, that's everything I wanted to ask erm, I don't know if there's anything else that you just wanted to add that you feel I've missed out or anything like that?

P: er, well what do you think? Do you think it will, I shall stay like this for the rest of my days?

I: oh, if I could tell people that! [*both laugh*] I'd be a millionaire

P: yeah, yeah, so what do you have to do, erm, just sort of make a book of this or

I: yeah, have we finished with this? [*I points to Dictaphone*]

P: yeah

I: okay

End of Interview

Qualitative Themes (Cross-sectional) – Condition (20/01/02)

CS001VB

- 54. Relapse – course of disease
- 93. Burning pain

CS002GB

- 15. Pain, hobbling
- 57. Function, walking
- 116. Choice between operation & > functioning

CS004AP

- 40. < problems
- 44. Limping
- 62. Inflammation
- 94. Specific problems
- 143. Function
- 282. Function – bath

CS005YS

- 3. Pain
- 28. Pain moving
- 39. Pain
- 66. Pain – specific activities
- 118. Affected by weather

HHR001JT

- 30. Incapacitating
- 39. Pain comes and goes
- 96. Pain spreading

HHR002DW

- 15. Pain
- 29. Flare
- 50. Function
- 127. Pain
- 131. Functioning – sitting/standing
- 136. Stiffness
- 147. Aching
- 206. Relapse

NL001DG

- 7. Symptoms – locking
- 10. Function
- 18. Symptoms – pain
- 22. Function
- 23. Altered function
- 44. > Pain
- 72. Bones
- 303. Pain varies

NL002GT

- 35. Pain
- 36. Mobility
- 65. Pain – hard to explain
- 102. > pain, but not completely
- 205? Pain control most important
- 344. Pain & function

NL003MT

- 54. Walking
- 90. Pain → disability
- 131. Pain

NL004CM

- 61. Sleeping problems
- 180. Pain

NL005BS

- 31. Function – walking
- 32. Affected by weather
- 34. They gnaw, but just aching, gradually got worse
- 36. They seem to have got to a certain stage and stayed there

Qualitative Interviews Condition (24/06/02)

CS001VB

54 it helped for a period of time (2) and then it sort of come back and started, you know, affect other areas...like the back of my neck, (along) here. Sometimes I can hardly touch xx here, it's a bit swollen sometimes.

92 I get a burning sensation at the (bottom of my foot)...and pain down my legs and then if I sit down, when I sit down they go very stiff to get up

CS002GB

14 at times it was very bad that I could hardly walk, er, I could, I could hobble painfully, that, that was all, erm and it's been going on and off I suppose for getting on for 20 years

86 I: What tends to be the worst aspect?

P: well, it's walking really, er, the knees have been much the worse...er () and er, walking you know...hobbling! (*both laugh*)

113 I think those are the main joints that get replaced aren't they?...er, so, I don't want to have to have that, but I'd rather have that than not being able to move

CS004AP

43 it's now gone in the right knee and I'm, that's where I'm at, at the moment

I: mm. Okay, and when you first er, were aware of the problems, what sort of problems was it causing you?

P: it was causing first of all a limp...I noticed. Erm, sitting or lying down was okay, I wasn't in any pain but the minute I started walking () short distance I would start to limp and it would be like, I can't explain it really, as if there were a nail right through my knee that wouldn't let it move, you know...restricted my movement dreadfully badly...and it got worse very quickly because my friends all started to notice, you know (*whispers*) "why are you limping?" erm, and you get used to it, this is the thing, you get sort of tolerating

61 that's how I noticed it in that my knee got **very** inflamed indeed

95 the pain is intense when I'm walking. When I'm sitting or lying down, it's okay. Standing's getting a bit awkward, it's really, I'm – getting on and off buses I don't find easy at all

143 I'm finding it very hard getting in and out of the bath now

281 I'm finding it hard to get in and out of the bath and these are things that I've got to...accept that I **must** do something about

CS005YS

3 It started erm, with a severe pain in my knee...it was really painful

26 the pain it left my knee...and erm, I could feel it way up in my groin, and then came in my back...and it was really dreadful, really terrible

38 the pain was really, really dreadful and I could (sort of) hardly do anything, and erm, the pain it was so severe that if I pick up anything that's heavy, you know just...when you xx it just go away from you

66 if I sort of do anything strenuous then it aggravates it

I: mm, okay, so what sort of things would that (be/mean) for you that would make the pain worse

P: it's there when I, it's sort of when I walk, walk up the stairs and I have to bend the knee

HHR001JT

30 it was incapacitating me really, and I spent a lot of time crying, having no sleep but erm (2) it was, it was very **deep** the pain it wasn't as if a paracetamol would have take it away...and I found that I was struggling to work 'cos I was working at Tesco's, cashier, er, that might sound like a cushy number but erm, too much sitting made it worse () and too much stand- well when I say too much...a certain amount of standing would relieve it but then it would come back, and then a certain amount of sitting would relieve it and then it would come back

96 : it comes and goes really, it's never, it's never, it's not actually **gone**, the intensity's gone but the discomfort's still there...and now I'm experiencing pains in my ankles...and waist pain

HHR002DW

15 I didn't know what to do, I'd never had such a bad pain. I mean I've had pain and it's been there for a few weeks...and then it'll go and it swells up and all the rest of it but it was really bad

29 it went on **still** was very painful, I really I think for 2 or 3 months and then quite suddenly, round about June () the pain went, but you see that's the sort of thing that happened anyway

49 I don't like these new buses, the seats are too low for me, I mean it sounds daft [*laughs*] 'cos I'm very mobile but if I get down on those, you know the new buses those small seats...if I get **down**, I find I've got to pull myself up with something, yet I don't do that in the normal way but I think they're exceptionally low

126 if I sit in a car on a long journey, it may not bother me that day but the next day () erm, I think to myself "oh my knee doesn't feel too good"...but I say, then I just sort of well, you know, get on with it! [*laughs*] and forget about it

131 I: and is it the aching that you tend to get more or do you, would you say it's the pain?

P: it's pain...

I: okay, and do you get any stiffness in the knee, or?

P: yeah stiffness and er, sometimes er you know, when I first go out in the morning it feels quite uncomfortable when I start walking...but again I think "oh well, it'll go off presently" and it usually does...or if I stand for too long it might ache a bit

I: so it's sort of being in one position

P: yeah, yeah

146 I didn't know what to do with them in bed of a night-time, they ached, actually ached...you know, it wasn't pain but it was just an aching in both of them

205 it comes and goes and I can have it really, really bad for weeks and weeks and then it just clears up and then it feels all tight...and gets swollen and that and then it sort of all goes almost as quickly as it came but it's nearly always erm, swollen, you know, it's not erm, it's not **badly** swollen

NL001DG

7 when it locks up but that...that is, that is the main problem where I, where I can't bend it () er, there's a few problems with it er (2) putting trousers on () sitting, lifting my leg to put the trousers on...I have to keep my foot on the ground, drop my trousers, put my foot in

18 when it locks up but that...that is, that is the main problem where I, where I can't bend it () er, there's a few problems with it er (2) putting trousers on () sitting,

lifting my leg to put the trousers on...I have to keep my foot on the ground, drop my trousers, put my foot in

81 when you feel it it's all crunchy and they, they said cartilage is worn away, that is the main problem, you can push the bones, they're crunching up altogether

310 just the moving around...I mean it's not paining me now until I bend it you know, but you know...but as I say it pains me, I told you it pains me in bed sometimes during the night, it wakes me up...but when I wake up to go to the toilet I get out of bed I can hardly walk with the pain in **both** knees that is

NL002GT

35 I couldn't walk at all when it first happened and er, then after, well since then I've had no, nothing but problems with my legs, my knees anyway

64 I'm not a, not really, used to all this pain, it's something that I can't really explain, because it's a pain that just don't seem to want to go away

101 it doesn't take the pain away but it just makes it not quite so strong, that's about, that's about as much as I can say

205 I **am** bothered about me right leg (but my left) 'cos I can't make out why all of a sudden me right leg is a pain centre now

341 it doesn't make no difference what you're doing, whatever movement you're making er, you can't do nothing you gotta go from A to B to start with, so that part from A to B is the part where you've got problems, you've got pain problems, and then when you get to er () providing the pain's only in your legs and not your arms, if you, once you're standing still, or standing **by** somewhere you can either er, steady yourself, **or** you can erm () help yourself around er () by () going along the benches or going along the worktops and things like that...but er, when I first had the pain (2) I, well I was having a hell of a job to do anything, hell of a job, but I am a bit better now

NL003MT

54 I can't walk too far

I: mm-hmm

P: to be honest, I mean I go round the cemetery twice a day and that is enough when I come back, that's, I can't go out shopping as well afterwards, I'm knackered! [*P laughs*] it's, you know, it's I'm ready to sit down when I get back

130 it's really piercing, it can wake you up at night with the pain, and that's after you've rested, 'cos I say to him "I shouldn't be like this when I've been in bed for 5 or 6 hours or so" you know? But I am

NL004CM

60 I've got it in my neck, I've had for a long time, so that of course is another problem when you're sleeping...in one position for too long and your neck gets fixed, so er, that's most of the problems that arise from...er, arthritis and er, I'm getting a bit worried now because they're [legs] going so much out that way, I've got a feeling that one of these days they're gonna fold, fold up underneath me, right? [*P laughs*]

180 it is getting very, very painful

NL005BS

31 it was just that you know when I was walking, aching and you know, I still find that when the weather's pretty wet it acts up more, you know?...they (gnaw), but no,

it was just aching you know, and they've gradually got worse...they seem to have got to a certain stage and they settled there, you know

SP001SK

3-4 well they're not too bad at the moment but I do find some days are better than others. Some days you know, no effect at all, but other days they ache and ache and ache

5-6 and I also find going **down** stairs () is more difficult than going upstairs and I sort of have to go sideways like a crab

15-17 found after a few years of getting in and out of the car and running up and down stairs they were starting to ache and then about four, five years ago they were **really, really** bad and I couldn't get in and out of the car

30-33 was it that made you come and see the doctor?

P: yes because they were getting very painful and I wasn't having any sleep with them and that because I didn't know which way to lay to ease them and, and I thought well I've **got** to go and see somebody about it and that's when I came here
39-40 I also found I couldn't kneel, I can't get down and kneel down because I can't get up again!

40-41 I found that over the years, obviously, they are getting worse

SP002ES

2 when I get up they hurt terrible

6 they're very painful

45-6 when I'm coming back home and I sit on a chair and get up oh! I just can't walk

163-4 I was worried more about my knees than anything else because I thought if I can't walk around, get around, you know

SP003BM

3-4 they're very, very tender, I cannot bear anybody to touch them

5-8 I can't kneel, there's **no** way that I can get down on them, it's a sensation that I, I can't describe, it's just very, very tender

I: right

P: to get on them it's impossible

12-14 it's just got worse over the years and it gives out as you're walking up the stairs you suddenly grip where the knees, and it's mainly at the back of the knee that they give out, that's about it

24 it's a sort of an ache, it's an ache

26 a **painful** ache and as I've got older so it's sort of got a bit worse

32-33 if I'm walking out it's hard to pull them along, it's like a whole leg action is affected by that, it's like as if you've got lead in your shoes

46-7 and it developed gradually?

P: it has, yes, over the years

55 the arthritis is creeping everywhere

62 it's a **lot** easier now to what it was say, a year ago

154 it was pain in the knees, and I can't remember all of it but I know there was pain and it was that

292-3 just putting a vacuum across the floor, it can affect that and then (when the vacuum goes back) I'm in too much pain, just sit down

SP004AS

3-9 that's the problem with my knee when I go to bed and if I sit too long it gets fixed, the left one **and** the right one, with the right one you see I had the accident, it's expected, but now with the left one and then I have to sort of wiggle my knee around somehow or another to get it in working order, I find that the left knee on the left hand side this part of the left hand side that's where the problem is, as you bend your knees so it, it affects it, the only solution I get out of it is taking the painkillers to help me

11-15 terrific, terrific pain () I can't, it seems as if the knee cap gets fixed and then I sort of waggle it about it's really **very** painful, very painful but once I straighten my knee it's not too bad

I: right so it's a sharp pain

P: mm, **very** sharp

43 it's gradually getting worse

47-9 what was it that made you decide to come and see the doctor about the, the arthritis?

P: well because it was so painful and then she, she thought it would be a good idea if I had therapy on it

55-8 the arthritis is gradually getting more and more

I: mm

P: I know it is by the way I walk about

60 if I stand too long that **will** be the trouble

121-2 I find it very hard () recently when I get out of bed and start walking, this left foot

SP005CS

15-6 it's really slowed me up, especially since I've had this knee go erm () I used to up till about two years ago I used to walk miles on the common nearly every day

33 now I can't sort of walk it off because I'm very slow walking now

36-8 it's made me very slow in moving, that's the only thing, I don't have any problem doing most sort of normal, you know, personal, domestic jobs, the worst job is putting my socks on! [*P laughs*] because I'm very stiff, you know?

112-4 , then something went in this knee [*indicates right knee*] again and er, that slowed me down and I didn't used to go walking so much, I still walk quite a bit but now I don't do so much

159 it's not a terribly big problem, only when it occurs, you know

SP006GK

7 it started off with very painful getting up and down stairs which was the start of it

15-8 stairs, downhill, uphill's not too bad, downhill is the problem

I: mm

P: especially if you're going, like, my son and I like to do a lot of walking, if you're coming down a rough hill, if you know what I mean

20-1 it's the sort of pain that makes you want to put your leg up for want of a better word, very, very sharp and nasty

55-6 fair wear and tear, that's what they said when I was about sixty three when it was first diagnosed

95-7 three years ago I would have thought nothing of fifteen miles, last year twelve miles was a heck of a struggle, I mean I had to sit down four or five times

121-5 now I mean last year's holiday started to, instead of doing ten mile a day do a five miler and then probably the next day progressively on

I: mm

P: I think you learn to adjust a bit

140-1 I've had the arthritis long enough now to know that I can control it

199-201 as I say the only thing is that now, any problems that you get with the other leg exacerbates that problem because you're feathering the, trying to feather that leg [*indicates left leg*] and throwing all the weight onto this leg [*points to right leg*]

212-4 going downstairs you sit for half an hour then you go, first thing in the morning you're very careful 'cos it'll give way on you because you've been resting them all night. It's hard to get a balance between **enough** exercise and too much exercise

SP007RD

11-4 I used to drive and I don't drive now, well nothing particular because I'm getting on now so I have to be careful, when I walk sometimes I have to walk slowly now because I had a fall, it was because I was running that I fell over, it wasn't pains in this knee but I feel it's weaker than this one [*points to left knee*]

20 it's an ache really

33-4 what was it that made you actually decide to come and see her?

P: because the pain was so awful

73 it's gone off now, I **think** it's the weather that controls it a lot

75 when it gets damp that seems to trouble me

115-7 I can get around alright at the moment

I: mm

P: I find if I sit for long periods then get up I get a bit of pain, stiffness really

120-2 when it gets better, you know, it does get better

I: mm

P: it clears completely, and then all of a sudden it comes on

I: okay, first of all if you can just tell me a bit about the problems that you have with your knees at the moment

P: well it started off with the right knee and only when I went for a check up on something else I found out it had progressed to the left knee and the left shoulder, the right knee is the one with all the problems

I: mm

P: erm, it started off with very painful getting up and down stairs which was the start of it, they sent me to hospital to have x-rays et cetera, et cetera which diagnosed the problem

I: mm, and how long ago was that?

P: oh, it must be about eight years ago, no it's about six years ago now

I: right

P: I was still at work

I: and you said it was the stairs mainly

P: stairs, downhill, uphill's not too bad, downhill is the problem

I: mm

P: especially if you're going, like, my son and I like to do a lot of walking, if you're coming down a rough hill, if you know what I mean

I: mm, yeah, and when you say pain, what sort of pain is it?

P: it's the sort of pain that makes you want to put your leg up for want of a better word, very, very sharp and nasty

I: mm, and, is that mainly the right knee?

P: yep

I: yep, how is the left knee in comparison?

P: the left knee is not too bad because I have just discovered only erm, nine months ago that I have claudication in the left knee, which is extremely painful, which again is feathering the left leg which again is increasing the pain with the arthritis [*P laughs*], you can't win!

I: erm, and when the arthritis was first diagnosed erm, what did you think would happen in the future?

P: erm, they gave me a course of tablets, I forget what they were now er, which didn't do a lot of good, Panadol would have done much better, but still never mind, and then they said that it would be a possibility, they were going to look into the possibility of replacing the knee

I: mm-hmm

P: and at the time they were thinking about it the chances were only seventy-thirty, so I said I'd put up with the pain, because I used to do work with the elderly and we had a young lady there, well, elderly lady that had both her knees replaced and ended up in a wheelchair, they couldn't mend her legs or anything, so I thought well I don't want that, if I can struggle around I'll carry on

I: mm, and did you have any ideas about sort of how the arthritis would develop, or progress?

P: no

I: no

P: no, no

I: and when they said oh, it is arthritis, can you remember what you thought, or how you felt then?

P: yeah, I basically accepted it because I've had a hard life being a gardener, I've been on my legs all my life one way or another, so I expected some wear in the joints

I: mm

P: erm, and a very nice man said well, you've only got osteoarthritis, you're very lucky you haven't got rheumatoid, I said yeah well, thanks very much! You know [*both laugh*] I don't want either

I: right, erm, and so it was, you feel that it was the sort of work you'd been doing

P: yeah, and fair wear and tear, that's what they said when I was about sixty three when it was first diagnosed

I: mm

P: I mean you take anything that's got sixty three years of hard wear on it, it's got to give way sometime

I: yeah () and you said that erm, they gave you some tablets to start off with and they didn't really do much good, do you take any medication for the arthritis now?

P: no

I: no

P: I don't, except for the medication I'm taking for this claudication I've got to take, which is anti-clotting and low cholesterol tablets, and tablets occasionally for migral-migraine, I don't like to take tablets because I'm an old fashioned believer that if you start taking tablets, after the first couple of months the body accepts those tablets and they don't do any good at all

I: mm () right () do you have any ideas about sort of how bad it would have to be before you would take tablets?

P: erm ()

I: for the knees specifically

P: how bad it would have to be

I: mm

P: it would have to impair my walking, because I do a lot of walking **and** cycling, it would have to impair that

I: mm

P: I mean apart from that as I say you do learn to control it in other ways, like resting it outstretched, resting it upraised () evening times if I sit watching telly for more than a half an hour I get up and the knee enough gives way, now you just sort of adjust your life to the way of it is [*P laughs*]

I: yes, and you said that when it was initially diagnosed you were sort of pretty concerned about how it might develop. As you are now, after six years or whatever, erm, how does that compare to maybe how you thought it would be?

P: favourable

I: mm

P: definitely favourable, because I thought it was a () rapid progression you know, to being completely useless on it

I: mm

P: erm, but it hasn't, touch wood! [*both laugh*]

I: erm, is it possible for you to sort of tell me the sort of changes that it's produced, or sort of changes you've had to make, I mean you mentioned the sort of resting and getting up

P: the changes that are becoming noticeable, as I said, my son who is in his forties lives with us, and we go away every year and, for example, say three years ago I would have thought nothing of fifteen miles, last year twelve miles was a heck of a struggle, I mean I had to sit down four or five times

I: mm

P: whereas before I had, I mean alright, the best walk I've ever done but the worst one as regards the leg, because we've done the erm, just outside, the Golden

Landscape, it's the highest cliff in England basically and as I say normally two years ago I'd have walked that with no, and the only way down is sort of straight down, and that really did play up

I: mm

P: that's where it's beginning to catch up with me

I: right, mm () and erm as you are now, perhaps looking into the future, do you have any ideas about how the arthritis will, will be in maybe five, ten years time?

P: if I'm around then

I: yes!

P: I reckon the rest of the body will be walking out by then! [*I laughs*] I'm sixty nine now. Well yeah, I suppose in the future if it did, I would then have to go back to the consultant and start thinking about having a knee replacement

I: mm-hmm

P: now that they are getting more, they've got more control over them and they are getting better

I: mm, and how would you feel about that sort of option?

P: () I'd be loathe to take it

I: mm

P: it would have to be a last resort

I: mm

P: i.e. that I couldn't walk at all, I mean, now I mean last year's holiday started to, instead of doing ten mile a day do a five miler and then probably the next day progressively on

I: mm

P: I think you learn to adjust a bit

I: mm, and how likely do you think it would be that you might have to consider

P: unlikely, unlikely

I: mm

P: I think the body will wear out before that! [*both laugh*]

I: but in terms of the knees you have a fairly, fairly sort of favourable outlook?

P: yeah, yeah

I: okay

P: it's the left leg worries me more now because the arteries are closing

I: mm

P: and I think that is more of a () shall we say, erm, it's got more potential for harm in the future than the arthritis has

I: mm

P: I mean if that started to progress then I would start getting really worried, I mean they say that if it progresses they will put a shunt in and things like that, but that would worry me more than the arthritis would, because I've had the arthritis long enough now to know that I can control it

I: mm, yeah, and () erm, we mentioned about when you first were diagnosed with the arthritis and perhaps what you thought would happen in terms of the actual, the problems with the knees. Can you remember what you sort of thought might happen in terms of treatment that you might receive for it?

P: I thought that I would get a lot more treatment for it than what I actually got, I mean I had six months of quite intensive physiotherapy, then it was, as is now unfortunately that's erm, all we can do, carry on with it, basically

I: mm

P: and they give you like little rubber balloons and all sorts of weird and wonderful things but who does that every day? [*P laughs*]

I: and how effective was the physiotherapy during that six months?

P: I would say on a scale of one to ten it was about six, no more than that, because it was good while it lasted but as it went on, the lasting time was getting progressively shorter, you know, when I first had it, it would last a couple of days before I really, and then it started to be one day and then () gradually came down to not being hardly worth it at all, really

I: mm

P: because as I say, like tablets, the body has accepted that

I: mm, and you had the, the painkillers, were there any other sort of types of medication that you tried, or that you were given?

P: yeah, er, some sort of, I don't know what they call it () sort of erm (3) not Ibuprofen, but where they

I: the anti-inflammatories?

P: yes, that's it, that's the word, anti-inflammatory tablets to try and take the inflammation down

I: mm

P: because it was very roughly explained to me but what it is, is that instead of it being a ball and socket you've got a straight joint that's grating on the other one, basically

I: mm

P: and they do erm, somebody suggested primrose oil, or sunflower oil, or one of the oils

I: mm

P: cod liver oil

I: mm, and did you try any of those?

P: I tried them, I tried them for about six months but they didn't make any difference

I: mm, and you said that you maybe expected to have some problems with the joints because of the [*tape changed over*] yeah, in terms of the sort of jobs that you've done, lifestyle and so on, erm (2) hang on, I've forgotten what I was going to say! So when you were younger, what sort of ideas did you have about arthritis and the sort of problems that it causes?

P: very few really, until I got to about fifty

I: mm

P: and then it was as I say, a lifetime in the outdoors, climbing and everything like, you suddenly start to, a friend of mine had it very bad, in his shoulder, and then he fell out of a tree basically, and then you start to think, you know () he's only ten years, five years older than me () basically the same lifestyle, **then** you start to think, I mean up till about fifty, fifty five you think you're invincible anyway

I: mm

P: and it's only as I say when I started to get into the fifty fives, but I used to be able to shin up trees with a power saw and everything like that and suddenly you get up the tree and think what the heck am I doing up here and how am I gonna get down again?! [*P laughs*] you don't **want** to accept it but you have to

I: mm

P: like walking, it's like anything else

I: yeah () erm, that's basically everything that I wanted to cover, I don't know if there's anything maybe I've missed out that you feel is important about

P: no, but as I say the only thing is that now, any problems that you get with the other leg exacerbates that problem because you're feathering the, trying to feather that leg [*indicates left leg*] and throwing all the weight onto this leg [*points to right leg*]

basically, I mean it's been worse for me in the last six months because of having this other problem with my left leg

I: is that in terms of pain?

P: pain, yeah, pain

I: right

P: it's what I can only describe as a masking pain, while I'm walking this leg is absolutely excruciating [*holds left leg*], really, really bad cramps, it's like multi-cramps basically, well you can guess because there's no blood supply getting to the muscles, you're then concentrating totally on that but then when you sit down this starts to ease off and then that one kicks in, **that's** when you notice it more as I say going downstairs you sit for half an hour then you go, first thing in the morning you're very careful 'cos it'll give way on you because you've been resting them all night. It's hard to get a balance between **enough** exercise and too much exercise basically

I: mm

P: that's the balance you're trying to strike

I: and in terms of sort of information you've been given over the years about managing the knee pain, sort of coping with the arthritis, erm, how's that been?

P: very poor. It seems to me, exactly like with this leg, I mean I went six months and it was diagnosed as claudication or whatever they call it, erm, put onto these tablets he said come back in six months so I went back a fortnight ago, oh yeah no examination, no nothing he just said you'll have to walk through the pain, your tablets are for life, bye-bye

I: mm

P: you know there's no sort of erm, follow-up or management procedure, he said if you wanna stick, use one, it's not that

I: mm

P: I mean it's exactly the same unfortunately with my brother-in-law who died a few years ago. He had terrible erm, ulcers and because of the area he was in, if we was in a certain area we could do it but really and truly, if he was [*tape changed over*] and as I say he was told that if he'd have been ten years younger they could have done a lot more for him, if he hadn't lived in this area they'd have done a lot more, and I think that's the way it's getting now, unfortunately

I: mm, so what sort of things would have been most helpful for you with the, with the arthritis, to know more about?

P: I think that if there was **someone** like, I don't know, not necessarily a nurse or someone like that, who could either give you a booklet say well look, if you do this it will be this if you'd done **that**, it would, you know, some sort of description of **how** you're gonna manage it

I: mm

P: **is** there anything that you **can** do? Would putting it up in the air be better than sitting it, things like that, that's far better explained

I: mm

P: instead of saying you've got osteoarthritis, have a course of physiotherapy, take ibuprofen or any other drug you want to, that's it, it's not really () I mean I like to be () if you like dot my eyes and tees, have it really fully explained how but I mean nowadays they just haven't got time

I: mm

P: I mean you're sort of, it's the same with you know, the doctors, if you go over ten minutes she's fidgeting and (2) erm, a big letter came round quite recently, when you

go to the doctors make sure you've only got one complaint! [*P laughs*] if you've got two make two appointments which is stupid

I: mm

P: I mean the old days when you had a chat to the doctor and he would, if you like, **fish** out what was wrong, now you've got to be so specific you might, and I'm more frightened I might miss something, you know

I: mm

P: that's the way it's going unfortunately

I: mm () okay, well that's all

P: okay?

I: yep

End of Interview

I: Okay, if you can just tell me how your knees are at the moment?

P: Awful! *[laughter]*

I: Right. In what way?

P: They seem to have got quite a bit worse, I'm finding a lot of problems coming downstairs, especially if I've been out for the day somewhere or I've been sitting for quite a length of time. They just don't want to seem to support me **coming down**. Going **upstairs** is not too bad. And the shoulder has certainly got a lot worse.

I: Right. How are they in terms of pain?

P: Really bad at times.

I: Right. Compared to how you were last year, how do you think you are now, or how your **knees** are?

P: I think in a scale of 1-10 I think they've gone down to about 5 now, and they were 9 last year basically.

I: Mmm. When I saw you, you said that you were having some problems with walking

P: Mmm.

I: You couldn't walk as far as you used to be able to. How is that now?

P: That's about the same. But of course it's a lot to do with this **leg** as well as anything else I suppose, and it could be that they've since found out that I've got degenerating MTJs in the left foot. And about four months ago they were going to make a new insole. Now whether **that** is because I'm trying to feather that, and therefore () I'm not too sure! *[laughter]*

I: The other thing last time was that you felt that you could **control** the knee pain, because you've had it a long time

P: Mmm.

I: How has that been in the last year or so – have you been able to control it?

P: I think it's okay. I mean I'd rather sort of control it than take tablets, as I say, I'm already taking tablets for this leg and I'm already taking cholesterol-reducing tablets.

I: Mmm.

P: And I'm, I suppose, of the old school where I don't like to take a concoction of tablets. () So I'm more or less trying to manage it without medicine, if you like.

I: Mmm. And how do you do that?

P: Basically, I've done a Pain Management course for my leg at the hospital. And the general consensus of opinion is: **Do** what you want to do - and if it becomes too much, sit down for five or ten minutes. If you're going on a long walk, for example – ten miles or something like that – sit down for ten or fifteen minutes. Instead of doing it in one hit, do it in three or four. And that's how I'm basically trying to **use** it without **abusing** it, if you like *[laughter]*.

I: What is it about medicines that you don't like?

P: I think that the body can't take too much. I mean, as I say, I'm already taking cholesterol tablets; I'm also taking these blood-reducing tablets. And I think if you take another one, although it says it's safe, I don't know whether they () on occasions I have to take Migralieve, but I mean I don't know () I suppose whether I like the whole cocktail of drugs going in together. I mean some bloke, if you said to him – or a female, mustn't say male or female – if, behind the Pharmacy counter they say: "Oh yeah, you can take those, they're alright," I'm always a little bit wary on the mixtures *[laughter]*.

I: Right. How bad would the pain or just how bad would the knees have to be for you to take pain-killers?

P: Inability to walk **completely**.

I: Right.

P: I mean if I found that even a short distance was getting too painful, then I would probably try Paracetamol, and if that didn't work, I would probably go back to the doctor to get a joint-reducer or something like that.

I: Mmm. Okay. In terms of treatment in the future, can you see yourself having to do that, or actually doing it?

P: [*Sighs*] () I don't know, you see. It's like I've only just been up about my leg, and the consultant said to me it's now down to **me**. I can either say to him: "I want a balloon." Or I can pain-manage.

I: Right.

P: And I said: "What's the options with the balloon?" He said: "Well, the first option, it goes in, you have no more pain. The second option is that it goes in and it **breaks**, we've got to open the leg up and take it out. The third option is that it goes in, goes completely wrong, and you lose the leg!" [*laughter*]

I: Right!

P: And, really, it's the same with the knee. Because I used to look after a lot of old people; I used to run a Senior Citizens' Club. And we had a lady there – and I mean this is going back, so probably () who had both knees replaced. And she finished up with life in a wheelchair; her legs locked. And yet again, a great friend of mine who's eighty-four, has just had both knees done and she says she feels fine!

I: Mmm.

P: But you hear so many stories of MRS and PEs and things like that in hospitals. And once you start opening a body up, you're opening up a can of worms – like anything else really, I suppose [*laughter*]

I: The last time I saw you as well, you felt that it was unlikely that you would need a knee replacement in the future. How do you feel about that now?

P: That is becoming more likely. I mean if, for example, after this holiday, that I **don't enjoy** it, then I might seriously start to consider. Because walking is my **enjoyment** really – not sitting on a beach sunning myself, I'm too old for that game! [*laughter*].

I: With the changes in the knees that have happened in the last year, I mean in addition to the knee replacement or the **thoughts** on that, has it had any effect on your ideas about what might happen in the future with the knees?

P: No. Except that, as I say, it may come to the stage where I will have that knee replacement, that's the only thing. I mean I can obviously see now, with hindsight, that it is not going to get any better; it won't get any better. Even with drugs, I mean it will only **subdue** the pain; it won't do any miracle cures or anything like that.

I: Did you think at any time point that it **would** get better?

P: I thought it **might** do.

I: Right.

P: But of course, looking right into it, I mean it's a loss of the fluid and the joint going square. And obviously the joint, the bones can't go round again; I mean they're now square, so there's no way they'll go round **again**. Unless I put some sandpaper in them [*laughter*] it might help! But apart from that!

I: Your new treatment! [*laughter*]

P: [*Laughter*]

I: What was it that kind of made you think about that?

P: Just the sheer pain factor really.

I: Right.

P: I mean beforehand the pain was, I suppose on a scale of 1-10 it was 2 or 3. And it's now gone up to sort of 4 or 5 – maybe even up to 6 now.

I: Right.

P: Perhaps at some stage it would have to come to that.

I: Mmm. You said that it's making things like coming downstairs difficult. What sort of effects are the pain and the problems with functioning having on your daily activities, your lifestyle, that kind of thing?

P: Not a lot. Not a lot. As I say, I am getting quite a bit more pain. But, if you like, it's manageable. I mean I'm still getting out and about. I went out with my grandson on Monday and we did 5 and a half miles round London. The **next** day I mean I just had to sit and rest, but I mean I wouldn't like it to come to the fact that I can only go out sort of once a week. That would start to **really** get me thinking! *[laughter]*

I: Yes () are there any other () ideas about treatment that you have, perhaps in the future or, you know, things that you feel that could be offered to you, anything like that? – apart from, say, a knee replacement.

P: Yeah. If, for example – I can't remember the case, my memory's gone as well as the knees! *[laughter]* If somebody brought out a trial drug for example, I mean I would be quite willing to give it a try. But apart from that, no.

I: Right. Have your feelings towards that, sort of trying new drugs, has that changed in the last year or so?

P: No. I mean I would always go with something new.

I: Right.

P: If it was clinically tested and it was approved by the doctor, of course. Not by some quack, you know! I mean if the doctor said to me: "Look, we've got this new drug out, it's done 'X', will you go in for the trials?" Then yes, I **would** go in for the trials.

I: Mmm, yeah. In terms, not so much of your **expectations** about the future but perhaps your **hopes** for the knees, what sort of things do you hope...?

P: I'm hoping – and it'll be () as I say I don't know – when I went up to the () and I can never say this word! – 'Optimist'?

I: 'Optometrist'? No?

P: The person that fits out () to get the soles of my

I: Oh right, yeah. I can never remember what it is!

P: No. It's something like 'Optometrist' or something. Anyway, he had a good examination of the knees – of everything to do with the legs obviously – and in walking, he said to me: "Do you know that your ankles are also turning outward? And you've got no flexion in the left leg, hardly, at all." Which I **didn't** know.

I: Mmm.

P: But I mean, he tried to put my leg where no leg was intended to go, but ()! *[laughter]* And he said that these insoles that they're making will help to straighten out the ankle. But whether it will do anything else to ease up () if you like, putting in shock-absorbers – which is what these are, I mean, basically. Whether **that** will do anything, I don't know. Because I've been waiting now since **May** for those to be made, so () *[laughter]*!

I: Mmm, yeah. Is the knee pain and the reduced functioning because of the knees, is that having any effect on you, sort of, emotionally?

P: It does make me feel a bit down to think that I can't do what I used to do.

I: Mmm.

P: It's like, I mean I was doing the tree in my garden. And I shot up the ladder like I always have done, and I thought: What am I doing up here, am I going to get **down**? And the whole family was saying: "Well, you're getting on, you shouldn't be..." –

you know. I mean things like that where I haven't restricted the things I **used to** do, sometimes it gets you down. But there again, you look at somebody like Doris who's just had her knees done and is still in a wheelchair; **that**, I could **not** put up with, somebody being dependent on somebody that () If I wanted to go out for the day, for example, I'd have to arrange for a wheelchair (and the same goes) for transport.

I: Mmm.

P: Something like that, then...

I: Yeah. When I saw you last year you felt that the fact you'd had an active lifestyle had, perhaps, been the main factor in getting the knee pain. Is that still the case, do you still think that that was...?

P: It could possibly be. It could be fair wear and tear. I mean at 70, I mean if you've got a car-engine at 70, you'd have probably () most of it replaced by now I should think! *[laughter]*

I: Yeah! Has that made any difference to, kind of, the activities that you do or the amount of...?

P: Not really. I used to do quite a bit of bike-riding, which I have cut down a bit because, again, that is a **lot** of knee-pressure.

I: Mmm.

P: And I find that () bike-riding **on my own** is no longer, if you like, a joy. But if my daughter, who is, like me, very active – I mean she's what, 34 or something like that – when she says: "Let's go out on the bike, Dad!" – and we go out **together**, I mean we did Windsor back, you know, and things like that – if I've got a **companion**.

I: Right.

P: Because I suppose it's the old thing of ego; I don't want to see my daughter going off and Dad being left behind, and it turns round the other way! I mean she wanted to get on the train at Hampton Court, but she decided to keep me company. That does the ego good! *[laughter]* And I don't want to sort of give in, in front of, like I said, I took my grandson out. And strangely enough, he's 31! *[laughter]* But I didn't want to give in, in front of him.

I: Yeah.

P: But things like that, no.

I: Mmm. And again, last time I saw you, you felt that your leg would give you more problems, perhaps, than the knee. Is that still the case?

P: No, I think it's 50:50 really.

I: Right.

P: I mean I'm, as I say, I'm waiting to see – and probably getting a little bit anxious – I **really** want to see how these insoles are going to...

I: Mmm.

P: If they **will** straighten the ankles up. I mean I didn't know that my ankles were crooked, but it's all to do with the degeneration of the metatarsal joints, which is, again, Arthritis. But whether that's going to () I think it () in a way I'm looking for a miracle - like, to think that two bits of rubber can make any difference! *[laughter]*

I: How will you feel if it **doesn't** work? Have you kind of (thought about that?)

P: No, a **little bit** disappointed. But it's like anything else, I have **tried** it.

I: Mmm.

P: It's something I have **tried**. Okay, it didn't work. It **could have** done, but it didn't.

I: Yeah. Fair enough!

P: *[laughter]*

I: I think that's probably everything. Actually, your, the knee pain that you have, does that tend to be constant, or does it come and go?

P: It depends, basically.

I: Ah-ha.

P: If, as I say, I'd been out and I have done what I call a '**good day**' – 6 or 8 miles – then probably I will still have the pain, if I got in at 8 o'clock at night, I would still have the pain when I went to bed.

I: Right.

P: But getting up in the morning, I've got to sort of wind the engine up. Once I get up and get going, it's not too bad.

I: Right, okay. But other than sort of depending on what activity you do, the pain is generally with you most of the time?

P: Oh yeah, but I mean to a varying degree.

I: Yeah. That's all that **I** wanted to ask you about. I don't know if there's anything that **you** feel has changed since I last saw you?

P: Not really, no.

I: No?

P: No.

I: Okay.

End of interview

Peter's Themes

Themes	Baseline	Follow-up
Features of condition	<i>Symptoms</i> : pain <i>Impact</i> : function esp. walking, impact of condition on lifestyle, lifestyle on OA Previous expectations: current situation – favourable	<i>Symptoms</i> : pain <+ <i>Impact</i> : function >, causing greater problems than before
Balance	<i>Different conditions</i> : trying to balance their effects	<i>Shift</i> : in balance of the two conditions <i>Striking balance between</i> : condition & views on treatment, hopes & realism, perseverance & adjustment
Future	<i>Condition</i> : progression, experiences of others,	<i>TKR</i> : < likelihood <i>Condition</i> : won't improve (previously thought it would), <i>Uncertainty</i> : what will happen with condition, whether different treatments will have an effect
Treatment	<i>Information</i> : gathered from various sources <i>Efficacy</i> : judging efficacy <i>Action of meds</i> : body gets used to them, prolonged use > efficacy <i>Probability of success</i> : TKR <i>Expectations</i> : amount of physio not matched by experiences <i>Criteria for accepting/needing treatment</i> : last resort, > function <i>Service care</i> (all poor): amount of treatment received, follow-up procedure, provision of info	<i>Criteria</i> : < pain <i>Use</i> : resisting use of painkillers <i>Action</i> : subdue but don't permanently relieve pain <i>Concerns</i> : re: mixing
Coping	<i>Mechanisms</i> : acceptance, adjustment, control	
Self-management		<i>Control</i> : less able to control condition than before <i>Techniques</i> : newly learned e.g. pacing, provided info that felt wasn't getting before
Emotional impact		<i>Feel down</i> : due to changes in function

APPENDIX 3: KNEE PAIN BELIEFS QUESTIONNAIRE

Knee Pain Expectations Checklist

We would like to know about the ideas you have about your knee pain. For each statement in bold, please tick the box that you agree with most.

Section 1

This section asks you to think back to when you first had knee pain, and how this compares to how you are now.

1. I expected to get knee pain as I got older

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. My knee pain is worse than I thought it would be

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. I expected to get better treatment for my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.* My ability to walk and climb stairs is better than I expected it to be

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Section 2

This section asks what you think will happen in the future with your knee pain

5. My knee pain will get worse in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. My knee pain will make activities such as walking & climbing stairs worse in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please turn over...

7.* My knee pain will not have a serious impact on my life in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

8. I will need to use walking aids (e.g. walking sticks, wheelchair) in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. There is no cure for my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

10. I have no idea what will happen in the future with my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. I expect to need surgery on my knees in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12.* I am optimistic about the future with regards to my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the questionnaire

Knee Pain Beliefs Questionnaire

We would like to know about the ideas you have about your knee pain. For each statement in bold, please tick the box that you agree with most.

The first question asks about your thoughts **before** you had knee pain

1. Before I had knee pain, I expected I would develop it as I got older

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This section asks you to think back to the beginning, when you first had knee pain, and how this compares to how you are now.

2. My knee pain now is worse than I thought it would be

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. I was pleased with the outcome of the treatment I received for my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. The treatment I received for my knee pain was not as helpful as I thought it would be

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. My ability to walk and climb stairs now is better than I expected it to be

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This section asks what you think will happen in the future with your knee **pain**

6. My knee pain will get worse in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. My knee pain will make activities such as walking & climbing stairs more difficult in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. My knee pain will not have a serious impact on my life in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. I will need to use walking aids (e.g. walking sticks, wheelchair) in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. There is no cure for my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. I expect to need surgery on my knees in the future

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. I am optimistic about the future with regards to my knee pain

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring Sheet for Expectations Checklist

- | | |
|--|--|
| 1. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree | 2. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree |
| 3. 0 – strongly disagree
1 – disagree
2 – neither agree nor disagree
3 – agree
4 – strongly agree | 4. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree |
| 5. 0 – strongly disagree
1 – disagree
2 – neither agree nor disagree
3 – agree
4 – strongly agree | 6. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree |
| 7. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree | 8. 0 – strongly disagree
1 – disagree
2 – neither agree nor disagree
3 – agree
4 – strongly agree |
| 9. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree | 10. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree |
| 11. 0 – strongly agree
1 – agree
2 – neither agree nor disagree
3 – disagree
4 – strongly disagree | 12. 0 – strongly disagree
1 – disagree
2 – neither agree nor disagree
3 – agree
4 – strongly agree |

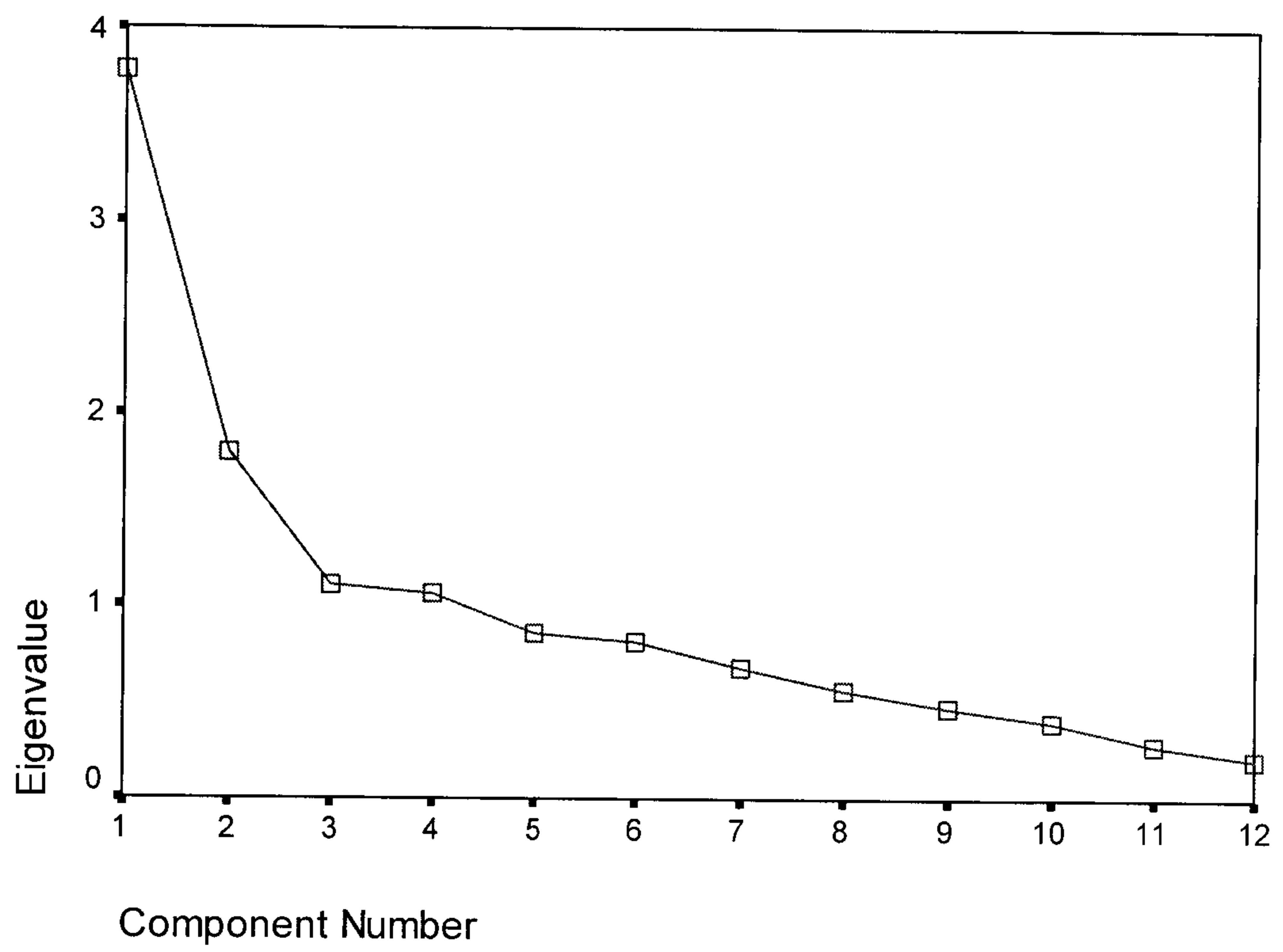
APPENDIX 4: FACTOR ANALYSIS OUTPUT

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.783	31.529	31.529	3.783	31.529	31.529	2.701	22.510	22.510
2	1.793	14.939	46.468	1.793	14.939	46.468	2.527	21.061	43.571
3	1.106	9.218	55.686	1.106	9.218	55.686	1.421	11.842	55.413
4	1.060	8.832	64.518	1.060	8.832	64.518	1.093	9.105	64.518
5	.857	7.144	71.661						
6	.808	6.735	78.397						
7	.682	5.682	84.079						
8	.560	4.664	88.743						
9	.473	3.944	92.686						
10	.399	3.325	96.011						
11	.277	2.308	98.319						
12	.202	1.681	100.000						

Extraction Method: Principal Component Analysis

Scree Plot



APPENDIX 5: QUESTIONNAIRES

We would like to know what activities you have been doing in the last month, how often you do them and how long for.

Activity	Please tick any activities you have done in the last month	For each activity you have ticked, please write how frequently you have done these in the last month (e.g. twice a week, once a month etc)	On average, for how long do you do each activity that you have ticked? (Please tick one of the boxes below) 0-15min 16-30min 31-45min 46-60+min						
Walking (Including walking to the shops)									
Social activities (e.g. clubs, visiting friends)									
Running/jogging									
Exercise bike									
Home exercises									
Gym									
Yoga / Pilates									
Keep fit									
Swimming									
Aqua aerobics									
Gardening									
Bowls									
Golf									
Dancing									
Other (please detail)									

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name..... Date.....

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling Yes or No, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom since my illness			This symptom is related to my illness	
	Yes	No		Yes	No
Pain	Yes	No		Yes	No
Sore Throat	Yes	No		Yes	No
Nausea	Yes	No		Yes	No
Breathlessness	Yes	No		Yes	No
Weight Loss	Yes	No		Yes	No
Fatigue	Yes	No		Yes	No
Stiff Joints	Yes	No		Yes	No
Sore Eyes	Yes	No		Yes	No
Wheeziness	Yes	No		Yes	No
Headaches	Yes	No		Yes	No
Upset Stomach	Yes	No		Yes	No
Sleep Difficulties	Yes	No		Yes	No
Dizziness	Yes	No		Yes	No
Loss of Strength	Yes	No		Yes	No

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1.
2.
3.

WOMAC Osteoarthritis Index Version LK3.0

Instructions to patients

In Sections A, B, and C, questions will be asked in the following format and you should give your answers by putting an 'X' in one of the boxes.

Note:

1. If you put your 'X' in the left-hand box, that is

None	Mild	Moderate	Severe	Extreme
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

then you are indicating that you have no pain.

2. If you put your 'X' in the right-hand box, that is

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

then you are indicating that your pain is extreme.

3. Please note:

- (a) that the further to the right you place your 'X', the more pain you are experiencing;
- (b) that the further to the left you place your 'X', the less pain you are experiencing;
- (c) please do not place your 'X' outside the box.

You will be asked to indicate on this type of scale the amount of pain, stiffness, or disability you have experienced in the last 48 hours.

Remember, the further you place your 'X' to the right, the more pain, stiffness, or disability you are indicating that you experienced. Finally, please note that you are to complete the questionnaire with respect to your study joint(s). You should think about your study joint(s) when answering the questionnaire, that is, you should indicate the severity of your pain, stiffness, and physical disability that you feel is caused by arthritis in your study joint(s). Your study joint(s) has been identified for you by your health care professional. If you are unsure which joint(s) is your study joint, please ask before completing the questionnaire.

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Section A

Instructions to patients

The following questions concern the amount of pain you have experienced due to arthritis in your study joint(s). For each situation please enter the amount of pain experienced in the last 48 hours. (Please mark your answers with an 'X').

Question: How much pain do you have?

1. Walking on a flat surface.

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

2. Going up or down stairs.

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

3. At night while in bed.

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

4. Sitting or lying.

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

5. Standing upright.

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐



Section B

Instructions to patients

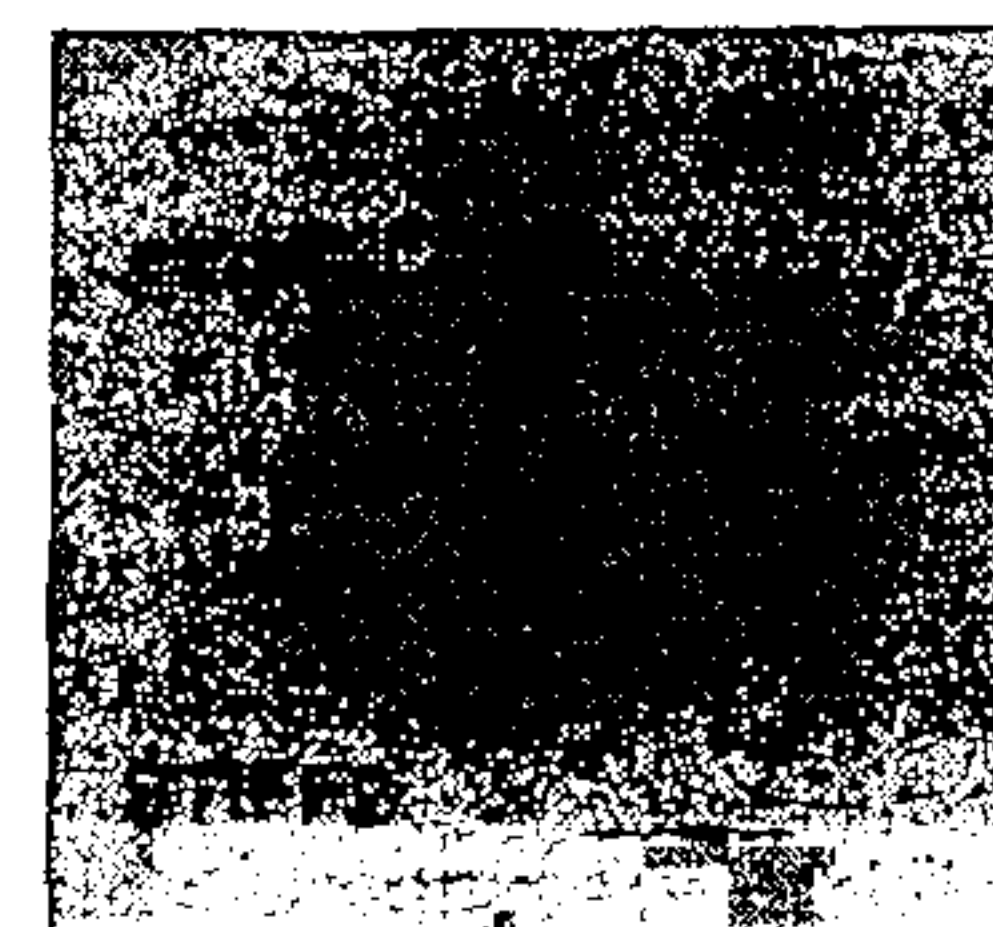
The following questions concern the amount of joint stiffness (not pain) you have experienced in the last 48 hours in your study joint(s). Stiffness is a sensation of restriction or slowness in the ease with which you move your joints. (Please mark your answers with an 'X'.)

6. How severe is your stiffness after first waking in the morning?

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

7. How severe is your stiffness after sitting, lying or resting later in the day?

None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐



Section C

Instructions to patients

The following questions concern your physical function. By this we mean your ability to move around and to look after yourself. For each of the following activities, please indicate the degree of difficulty you have experienced in the last 48 hours due to arthritis in your study joint(s). (Please mark your answers with an 'X'.)

Question: What degree of difficulty do you have?

8. Descending stairs.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Ascending stairs.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Rising from sitting.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Standing.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Bending to floor.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Walking on flat.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Getting in/out of car.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Going shopping.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. Putting on socks/stockings.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Rising from bed.

None	Mild	Moderate	Severe	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Taking off socks/stockings.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

19. Lying in bed.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

20. Getting in/out of bath.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

21. Sitting.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

22. Getting on/off toilet.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

23. Heavy domestic duties.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

24. Light domestic duties.
None Mild Moderate Severe Extreme
☐ ☐ ☐ ☐ ☐

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

HAD Scale

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.
This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

Most of the time
A lot of the time
Time to time, Occasionally
Not at all

I feel as if I am slowed down:

Nearly all the time
Very often
Sometimes
Not at all

I still enjoy the things I used to enjoy:

Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all
Occasionally
Quite often
Very often

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I have lost interest in my appearance:

Definitely
I don't take so much care as I should.....
I may not take quite as much care
I take just as much care as ever

I can laugh and see the funny side of things:

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

I feel restless as if I have to be on the move:

Very much indeed
Quite a lot
Not very much
Not at all

Worrying thoughts go through my mind:

A great deal of the time
A lot of the time
From time to time but not too often ..
Only occasionally

I look forward with enjoyment to things:

As much as ever I did
Rather less than I used to
Definitely less than I used to
Hardly at all

I feel cheerful:

Not at all
Not often
Sometimes
Most of the time

I get sudden feelings of panic:

Very often indeed
Quite often
Not very often
Not at all

I can sit at ease and feel relaxed:

Definitely
Usually
Not often
Not at all

I can enjoy a good book or radio or TV programme:

Often
Sometimes
Not often
Very seldom

Do not write below this line

From the statements below circle the statement on right that most accurately reflects your opinion

I. Self-efficacy for exercise:

If I want to exercise I know I can do it.	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
I'm not sure I could exercise regularly, even if I wanted to	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
I feel unsure about my ability to exercise	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
A person with medical problems like mine cannot exercise regularly	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree

II. Barriers to exercise:

Exercise takes too much time	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise is a waste of time	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise is boring	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree

III. Benefits of exercise:

Exercise helps people feel more attractive	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise makes a person feel good physically and emotionally	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise gives a person more energy	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree

From the statements below (on left) circle the statement (on right) that most accurately reflects your opinion

IV. The impact of exercise on arthritis:

Regular exercise will probably make my arthritis worse in the future	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
People with arthritis who exercise will remain more independent	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
People with arthritis should be encouraged to exercise regularly	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise is dangerous for people with arthritis	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise causes arthritic flare-ups	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
People with arthritis who exercise are healthier	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree
Exercise is a way to lessen the impact of arthritis	Strongly Disagree	Disagree	Don't agree or disagree	Agree	Strongly Agree

APPENDIX 6: REGRESSION MODELS OUTPUT

Regression Model 1 - Output

Descriptive Statistics

	Mean	Std. Deviation	N
baseline mean duration of activiteis	4.1641	2.25796	76
baseline self-efficacy expectations	14.17	3.247	76
baseline outcome expectations	27.24	3.068	76
baseline expectations factor 1	1.6875	.66348	76
baseline expectations factor 3	1.9079	.80710	76

Variables Entered/Removed(b)

Model	Variables Entered	Variables Removed	Method
1	outcome expectations, self-efficacy expectations(a)	.	Enter
2	expectations factor 1, expectations factor 3(a)	.	Enter

a All requested variables entered.
b Dependent Variable: mean duration of activities

Model Summary(c)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Durbin-Watson
					R Square Change	F Change	df1	df2	
1	.285(a)	.081	.056	2.19356	.081	3.234	2	73	.045
2	.458(b)	.210	.166	2.06244	.129	5.788	2	71	.005

a Predictors: (Constant), baseline outcome expectations, baseline self-efficacy expectations
b Predictors: (Constant), outcome expectations, self-efficacy expectations, expectations factor 1, expectations factor 3
c Dependent Variable: mean duration of activities

ANOVA(c)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	31.125	2	15.562	3.234	.045(a)
	Residual	351.254	73	4.812		
	Total	382.378	75			
2	Regression	80.369	4	20.092	4.724	.002(b)
	Residual	302.010	71	4.254		
	Total	382.378	75			

a Predictors: (Constant), outcome expectations, self-efficacy expectations
b Predictors: (Constant), outcome expectations, self-efficacy expectations, expectations factor 1, expectations factor 3
c Dependent Variable: baseline mean duration of activities

Coefficients (a)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error				Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	-1.150	2.292		-.502	.617	-5.719	3.418					
	self-efficacy expectations	.114	.083	.164	1.375	.173	-.051	.279	.226	.159	.154	.885	1.129
	outcome expectations	.136	.088	.184	1.548	.126	-.039	.311	.240	.178	.174	.885	1.129
2	(Constant)	-1.771	2.432		-.728	.469	-6.620	3.078					
	self-efficacy expectations	.143	.080	.205	1.796	.077	-.016	.301	.226	.208	.189	.850	1.177
	outcome expectations	.125	.085	.170	1.477	.144	-.044	.294	.240	.173	.156	.842	1.187
	expectations factor 1	1.021	.362	.300	2.822	.006	.300	1.743	.259	.318	.298	.984	1.017
	expectations factor 3	-.638	.305	-.228	-2.091	.040	-1.246	-.030	-.198	-.241	-.221	.936	1.068

a Dependent Variable: mean duration of activities

Regression Model 2 – Output

Descriptive Statistics

	Mean	Std. Deviation	N
baseline mean duration of activities	4.1587	2.27267	75
baseline total (pain, stiffness, function)	35.77	17.684	75
baseline expectations factor 1	1.6867	.66791	75
baseline expectations factor 3	1.8867	.79088	75
baseline ipq consequences	3.0775	.85805	75
baseline HAD depression	4.92	3.348	75
baseline self-efficacy scale total	65.23	7.466	75

Variables Entered/Removed(b)

Model	Variables Entered	Variables Removed	Method
1	total (pain, stiffness, function)(a)	.	Enter
2	expectations factor 3, expectations factor 1, self-efficacy scale total, HAD depression, ipq consequences(a)	.	Enter

a All requested variables entered.
b Dependent Variable: baseline mean duration of activities

Model Summary(c)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Durbin-Watson
					R Square Change	F Change	df1	df2	
1	.258(a)	.067	.054	2.21049	.067	5.222	1	73	.025
2	.495(b)	.245	.179	2.05958	.179	3.218	5	68	.011

a Predictors: (Constant), total (pain, stiffness, function)

b Predictors: (Constant), total (pain, stiffness, function), expectations factor 3, expectations factor 1, self-efficacy scale total, HAD depression, ipq consequences

c Dependent Variable: mean duration of activities

ANOVA(c)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	25.516	1	25.516	5.222	.025(a)
	Residual	356.696	73	4.886		
	Total	382.211	74			
2	Regression	93.765	6	15.628	3.684	.003(b)
	Residual	288.446	68	4.242		
	Total	382.211	74			

a Predictors: (Constant), total (pain, stiffness, function)

b Predictors: (Constant), total (pain, stiffness, function), expectations factor 3, expectations factor 1, self-efficacy scale total, HAD depression, ipq consequences

c Dependent Variable: mean duration of activities

Coefficients(a)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant) total (pain, stiffness, function)	5.347	.579		9.232	.000	4.192	6.501					
		-.033	.015	-.258	-2.285	.025	-.062	-.004	-.258	-.258	-.258	1.000	1.000
2	(Constant) total (pain, stiffness, function)	.431	3.222		.134	.894	-5.997	6.860					
		-.005	.019	-.036	-.248	.805	-.042	.033	-.258	-.030	-.026	.528	1.892
	expectations factor 1	.867	.395	.255	2.196	.031	.079	1.655	.259	.257	.231	.824	1.213
	expectations factor 3	-.700	.307	-.244	-2.280	.026	-1.313	-.087	-.208	-.266	-.240	.972	1.029
	ipq consequences	-.426	.366	-.161	-1.163	.249	-1.156	.305	-.290	-.140	-.123	.581	1.721
	HAD depression	-.004	.085	-.006	-.048	.962	-.174	.166	-.197	-.006	-.005	.703	1.422
	self-efficacy scale												
	total	.078	.036	.256	2.162	.034	.006	.150	.279	.254	.228	.792	1.263

a Dependent Variable: baseline mean duration of activities

Regression Model of Baseline Variables on Time 2 Activity Levels

Descriptive Statistics

	Mean	Std. Deviation	N
post-intervention mean total of activities	4.7768	2.24224	57
baseline mean total of activities	4.4332	2.11331	57
baseline ipq personal control	3.2734	.61642	57
baseline ipq treatment	3.3146	.60431	57
baseline expectations factor 1	1.7368	.68534	57
baseline expectations factor 3	1.8772	.80888	57

Variables Entered/Removed(b)

Model	Variables Entered	Variables Removed	Method
1	baseline mean total of activities(a)	.	Enter
2	baseline ipq personal control, baseline ipq treatment(a)	.	Enter
3	baseline expectations factor 3, baseline expectations factor 1(a)	.	Enter

a All requested variables entered.
b Dependent Variable: post-intervention mean total of activities

Model Summary(d)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Durbin-Watson
					R Square Change	F Change	df1	df2	
1	.257(a)	.066	.049	2.18674	.066	3.879	1	55	.054
2	.384(b)	.148	.099	2.12796	.082	2.540	2	53	.088
3	.429(c)	.184	.105	2.12183	.037	1.153	2	51	.324

a Predictors: (Constant), baseline mean total of activities

b Predictors: (Constant), baseline mean total of activities, baseline ipq personal control, baseline ipq treatment

c Predictors: (Constant), baseline mean total of activities, baseline ipq personal control, baseline ipq treatment, baseline expectations factor 3, baseline expectations factor 1

d Dependent Variable: post-intervention mean total of activities

ANOVA(d)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	18.548	1	18.548	3.879	.054(a)
	Residual	263.000	55	4.782		
	Total	281.548	56			
2	Regression	41.553	3	13.851	3.059	.036(b)
	Residual	239.995	53	4.528		
	Total	281.548	56			
3	Regression	51.937	5	10.387	2.307	.058(c)
	Residual	229.611	51	4.502		
	Total	281.548	56			

a Predictors: (Constant), baseline mean total of activities

b Predictors: (Constant), baseline mean total of activities, baseline ipq personal control, baseline ipq treatment

c Predictors: (Constant), baseline mean total of activities, baseline ipq personal control, baseline ipq treatment, baseline expectations factor 3, baseline expectations factor 1

d Dependent Variable: post-intervention mean total of activities

Coefficients(a)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error				Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant) baseline mean total of activities	3.570	.678		5.265	.000	2.211	4.928					
		.272	.138	.257	1.969	.054	-.005	.549	.257	.257	.257	1.000	1.000
2	(Constant) baseline mean total of activities	-.580	1.975		-.294	.770	-4.541	3.382					
		.261	.135	.246	1.935	.058	-.010	.532	.257	.257	.245	.992	1.008
	baseline ipq personal control	.763	.488	.210	1.566	.123	-.214	1.741	.253	.210	.199	.895	1.117
	baseline ipq treatment	.513	.499	.138	1.027	.309	-.488	1.513	.226	.140	.130	.889	1.124
3	(Constant)	-1.108	2.021		-.548	.586	-5.165	2.948					
	baseline mean total of activities	.354	.148	.333	2.393	.020	.057	.650	.257	.318	.303	.824	1.213
	baseline ipq personal control	.690	.491	.190	1.406	.166	-.295	1.675	.253	.193	.178	.879	1.138
	baseline ipq treatment	.668	.539	.180	1.237	.222	-.415	1.751	.226	.171	.156	.757	1.322
	baseline expectations factor 1	-.537	.473	-.164	-1.135	.262	-1.486	.413	.037	-.157	-.144	.765	1.306
	baseline expectations factor 3	.415	.377	.150	1.101	.276	-.341	1.171	.109	.152	.139	.866	1.154

a Dependent Variable: post-intervention mean total of activities

Regression Model of Baseline Variables on Time 3 Activity Levels

Descriptive Statistics

	Mean	Std. Deviation	N
follow-up mean total of activities	4.6291	2.14138	57
baseline mean total of activities	4.4332	2.11331	57
baseline womac pain	7.07	3.273	57
baseline expectations factor 4	2.5965	1.17807	57
baseline HAD anxiety	6.12	4.322	57
baseline self-efficacy scale total	64.98	7.724	57
baseline expectations factor 1	1.7368	.68534	57
baseline expectations factor 3	1.8772	.80888	57

Variables Entered/Removed(b)

Model	Variables Entered	Variables Removed	Method
1	baseline mean total of activities(a)	.	Enter
2	baseline womac pain(a)	.	Enter
3	baseline expectations factor 4, baseline HAD anxiety, baseline self-efficacy scale total(a)	.	Enter
4	baseline expectations factor 3, baseline expectations factor 1(a)	.	Enter

a All requested variables entered.
b Dependent Variable: follow-up mean total of activities

Model Summary(e)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.227(a)	.051	.034	2.10452	.051	2.979	1	55	.090	
2	.286(b)	.082	.048	2.08933	.031	1.803	1	54	.185	
3	.461(c)	.213	.136	1.99091	.131	2.824	3	51	.048	
4	.558(d)	.311	.213	1.90009	.098	3.496	2	49	.038	2.057

a Predictors: (Constant), baseline mean total of activities

b Predictors: (Constant), baseline mean total of activities, baseline womac pain

c Predictors: (Constant), baseline mean total of activities, baseline expectations factor 4, baseline HAD anxiety, baseline self-efficacy scale total

d Predictors: (Constant), baseline mean total of activities, baseline womac pain, baseline expectations factor 4, baseline HAD anxiety, baseline self-efficacy scale total, baseline expectations factor 3, baseline expectations factor 1

e Dependent Variable: follow-up mean total of activities

ANOVA(e)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	13.193	1	13.193	2.979	.090(a)
	Residual	243.595	55	4.429		
	Total	256.788	56			
2	Regression	21.063	2	10.531	2.413	.099(b)
	Residual	235.725	54	4.365		
	Total	256.788	56			
3	Regression	54.638	5	10.928	2.757	.028(c)
	Residual	202.150	51	3.964		
	Total	256.788	56			
4	Regression	79.882	7	11.412	3.161	.008(d)
	Residual	176.906	49	3.610		
	Total	256.788	56			

a Predictors: (Constant), baseline mean total of activities

b Predictors: (Constant), baseline mean total of activities, baseline womac pain

c Predictors: (Constant), baseline mean total of activities, baseline womac pain, baseline expectations factor 4, baseline HAD anxiety, baseline self-efficacy scale total

d Predictors: (Constant), baseline mean total of activities, baseline womac pain, baseline expectations factor 4, baseline HAD anxiety, baseline self-efficacy scale total, baseline expectations factor 3, baseline expectations factor 1

e Dependent Variable: follow-up mean total of activities

Coefficients(a)

Model		Coefficients(a)										Collinearity Statistics	
		Unstandardized Coefficients		Standardized Coefficients		t	Sig.	95% Confidence Interval for B		Correlations			VIF
		B	Std. Error	Beta				Lower Bound	Upper Bound	Zero-order	Partial	Tolerance	
1	(Constant)	3.611	.652		5.534	.000		2.303	4.919				
	baseline mean total of activities	.230	.133	.227	1.726	.090		-.037	.496	.227	.227	1.000	1.000
2	(Constant)	4.593	.977		4.702	.000		2.634	6.551				
	baseline mean total of activities	.194	.135	.192	1.444	.155		-.076	.465	.227	.193	.962	1.039
	baseline womac pain (Constant)	-.117	.087	-.178	-1.343	.185		-.291	.058	-.216	-.180	.962	1.039
3	(Constant)	-.131	2.815		-.047	.963		-5.783	5.521				
	baseline mean total of activities	.167	.130	.165	1.286	.204		-.094	.428	.227	.177	.937	1.068
	baseline womac pain	-.054	.090	-.083	-.601	.551		-.235	.127	-.216	-.084	.812	1.232
	baseline expectations factor 4	.419	.236	.230	1.772	.082		-.056	.893	.299	.241	.913	1.095
	baseline HAD anxiety	-.042	.069	-.084	-.601	.550		-.181	.097	-.244	-.084	.790	1.266
	baseline self-efficacy scale total	.055	.039	.198	1.404	.166		-.024	.133	.343	.193	.776	1.289
4	(Constant)	.800	3.006		.266	.791		-5.241	6.841				
	baseline mean total of activities	.317	.136	.313	2.324	.024		.043	.591	.227	.315	.775	1.290
	baseline womac pain	-.089	.087	-.136	-1.019	.313		-.265	.087	-.216	-.144	.787	1.271
	baseline expectations factor 4	.443	.226	.244	1.963	.055		-.011	.897	.299	.270	.911	1.097
	baseline HAD anxiety	-.049	.067	-.099	-.733	.467		-.184	.086	-.244	-.104	.769	1.300
	baseline self-efficacy scale total	.039	.038	.141	1.024	.311		-.038	.116	.343	.145	.745	1.342
	baseline expectations factor 1	-.862	.407	-.276	-2.117	.039		-1.681	-.044	-.130	-.289	.828	1.208
	baseline expectations factor 3	.622	.332	.235	1.870	.067		-.046	1.289	.125	.258	.892	1.121

a Dependent Variable: follow-up mean total of activities

ANOVA for Current Beliefs (longitudinal analysis)

Within-Subjects Factors

Measure: MEASURE_1

current_beliefs	Dependent Variable
1	t1expec2
2	t2expec2
3	t3expec2

Descriptive Statistics

	Mean	Std. Deviation	N
baseline expectations factor 2	1.5881	.77756	57
post-intervention expectations factor 2	2.2076	.85160	57
follow-up expectations factor 2	2.3005	.78483	57

Multivariate Tests(b)

Effect		Value	F	Hypothesis df	Error df	Sig.
current_beliefs	Pillai's Trace	.363	15.638(a)	2.000	55.000	.000
	Wilks' Lambda	.637	15.638(a)	2.000	55.000	.000
	Hotelling's Trace	.569	15.638(a)	2.000	55.000	.000
	Roy's Largest Root	.569	15.638(a)	2.000	55.000	.000

a. Exact statistic

b. Design: Intercept

Within Subjects Design: current_beliefs

Mauchly's Test of Sphericity(b)

Measure: MEASURE_1							
Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon(a)		
					Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Current beliefs	.859	8.380	2	.015	.876	.902	.500

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.
a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b. Design: Intercept
Within Subjects Design: current_beliefs

Tests of Within-Subjects Effects

Measure: MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Current beliefs	Sphericity Assumed	17.098	2	8.549	20.933	.000
	Greenhouse-Geisser	17.098	1.752	9.757	20.933	.000
	Huynh-Feldt	17.098	1.804	9.476	20.933	.000
	Lower-bound	17.098	1.000	17.098	20.933	.000
Error(current beliefs)	Sphericity Assumed	45.740	112	.408		
	Greenhouse-Geisser	45.740	98.132	.466		
	Huynh-Feldt	45.740	101.046	.453		
	Lower-bound	45.740	56.000	.817		

Pairwise Comparisons

Measure: MEASURE_1		(J) current_beliefs	Mean Difference (I-J)	Std. Error	Sig.(a)	95% Confidence Interval for Difference(a)	
(I) current_beliefs						Lower Bound	Upper Bound
1	2		-.619(*)	.133	.000	-.948	-.291
	3		-.712(*)	.128	.000	-1.027	-.398
2	1		.619(*)	.133	.000	.291	.948
	3		-.093	.095	.995	-.327	.141
3	1		.712(*)	.128	.000	.398	1.027
	2		.093	.095	.995	-.141	.327

Based on estimated marginal means

* The mean difference is significant at the .05 level.

a Adjustment for multiple comparisons: Bonferroni.

PUBLISHED ABSTRACTS

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Mitchell, H.L., Khoshaba, B.B., & Weinman, J.A. (2003, April). Outcome and treatment expectations for Osteoarthritis in primary care patients. Poster presentation at *British Society for Rheumatology Conference*, Manchester, U.K.

